



# Kentucky Supporting Documents: CYSHCN

---

Commission for Children with Special Health Care Needs

- 1. Overview of CCSHCN**
- 2. Success Story/Data Brief: Transitions**
- 3. Success Story/Data Brief: Access to Care**
- 4. Success Story/Data Brief: Insurance**
- 5. Data Brief: CYSHCN**
- 6. Results & Process: CYSHCN Needs Assessment**
- 7. CCSHCN Strategic Plan Overview**
- 8. Example of Regional Report—Patient Survey Data**
- 9. Graduate Student in Epidemiology Analysis of NS-  
CSHCN & NSCH**
- 10. Data Brief: CYSHCN Disparities**



# Commission for Children with Special Health Care Needs

## Special Children... Special Needs... Special Care

**What we treat:** Many conditions can be treated by CCSHCN through direct care, financial assistance, and/or case management. Clinics take place in 12 Commission offices and other sites across the state, using a treatment team to provide care. Our programs include:

Asthma (Severe)  
Craniofacial  
Neurology  
Spina Bifida

Cardiology  
Cystic Fibrosis  
Neurosurgery  
Communication Disorders

Cerebral Palsy  
Eye  
Orthopedic

Cleft Lip & Palate  
Hemophilia  
Otology

**Direct Care:** CCSHCN clinics offer a family centered, team approach to care, beginning with medical care from pediatric specialists. During each visit, children and families may also receive nutritional services, social services, and more from a staff of caring professionals. Some clinics include more than one physician to address multiple needs. What types of services can be included? Based on your child's needs, your child may have:

Hospitalization  
Lab Tests/X-rays  
Medical Supplies/DME  
Interpretation

Physician Services  
Physical Therapy  
Dental  
Transportation

Surgery  
Speech Therapy  
Orthodontia  
Supplements

Hearing Tests  
Occupational Therapy  
Medication Management  
Nutrition Consultation

**Care Coordination:** Through care coordination a registered nurse works with the family to create the care plan that is right for the child and family. The plan will include the recommendations of doctors and other professionals and will respect the needs of your child and family.

**EHDI/Audiology:** Did you know that about 3 in 1,000 babies are born with permanent hearing loss? It's one of the most common birth defects in America. CCSHCN's Audiology program includes hearing conservation, diagnostic testing, hearing aid fittings, and programming for cochlear implants.

**First Steps Point of Entry:** First Steps is a statewide early intervention program serving children with developmental disabilities from birth to age 3. CCSHCN is the point of entry (POE) for families in the KIPDA service region.

**Therapeutic Services:** CCSHCN offers speech-language therapy, occupational therapy, and physical therapy as part of our commitment to meeting all the medical needs of our patients.

**Transition:** Our patients and their families are connected with resources to help them plan for the future. CCSHCN is also home to the Family 2 Family Health Information Center which helps parents connect with other parents who have experienced similar challenges.

**Foster Care Support:** CCSHCN supports children with special needs in the child welfare system through our collaboration with the Department for Community Based Services (DCBS). Included in this program are nurse consultants and supports for children who are medically fragile.



# Kentucky Supporting Documents: CYSHCN

---

Commission for Children with Special Health Care Needs

**On the Following Page:**

**Success Story/Data Brief: Transitions**





# Transitions for CSHCN: A Kentucky Story

## Commission for Children with Special Health Care Needs

Planning for the future, making positive health choices, managing health and health care, and understanding changes are key tasks during the critical period of transition to adulthood.

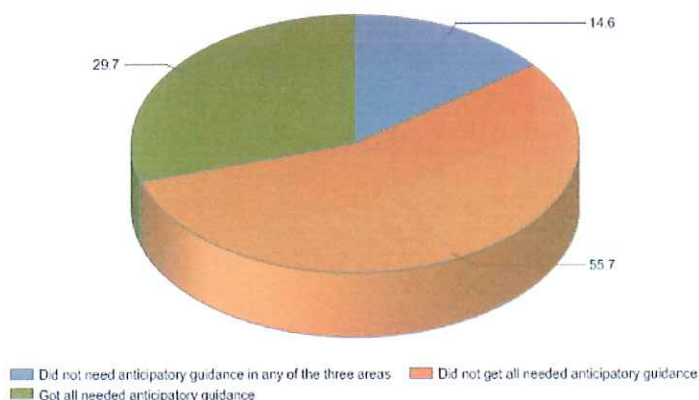
“Jennifer” is a Kentuckian who required several surgeries and medical/dental/orthodontic interventions due to Cleft Lip and Palate conditions, and wears a hearing aid. As part of her enrollment in CSHCN’s clinical program, Jennifer and her parents worked with staff, learning how to become an active participant in the team of providers to plan for the challenges that she faced as a young adult. Now 23 years old, Jennifer has graduated college with a Bachelor’s in Social Work and is scheduled to receive her Master’s degree in 2017. As a future social worker, Jennifer wants to work with CSHCN and their families and focus on behavioral health needs.

Jennifer received and participated in individualized preparation and worked very hard and now represents a success story. Consider, however, the challenges families of youth with special health care needs in Kentucky face in obtaining the services needed. As part of CSHCN’s Five-Year Action Plan, the agency continues to develop strategies, continues with preparation activities, and to assist families through education and navigation.

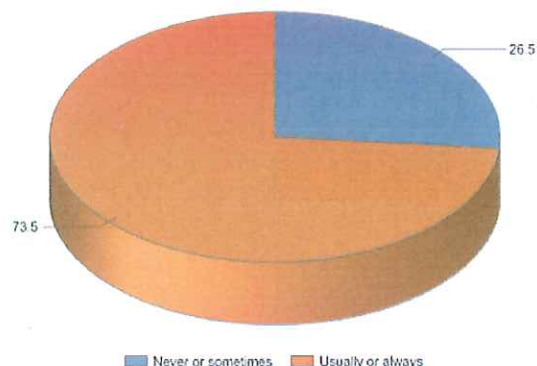
<i>Prevalence of Children with Special Health Care Needs (CSHCN), among all children age 0-17</i>	19.5	197,916
	% of CSHCN	# of CSHCN
<i>Youth with special health care needs who do not receive the services necessary to make appropriate transitions to adult health care, work and independence -- CSHCN age 12-17 years only</i>	62.9	43,945
<i>Doctors did not discuss transition to providers who treat adults, age 12-17 years</i>	45.6	32,208
<i>Doctors have not discussed youth's health care needs as he/she becomes an adult, age 12-17</i>	53.9	38,751
<i>No discussion about youth's health insurance as he/she becomes an adult, age 12-17 years</i>	75.5	54,249

### Impact on Families with CSHCN

Transition Part A: Anticipatory guidance for transition to adult health care  
CSHCN age 12-17 years  
Kentucky



How often youth's doctor encourages [him/her] to take age-appropriate responsibility for [his/her] health needs  
CSHCN age 12-17 years  
Kentucky







# Kentucky Supporting Documents: CYSHCN

---

Commission for Children with Special Health Care Needs

**On the Following Page:**

**Success Story/Data Brief: Access to Care**



# Access to Care for CSHCN: A Kentucky Story

## Commission for Children with Special Health Care Needs

Finding and accessing care for children and youth with complex health care needs can be difficult and frustrating, as often multiple doctors and agencies are involved. Provider shortages or less than robust provider networks often means traveling long distances, wait times, or fragmented services. CCSHCN, the Title V agency for CYSHCN, ensures gap-filling services are available for specialty care of chronic conditions, and ensures quality care and care coordination to thousands of Kentuckians in their communities. Whether CCSHCN is providing the services directly, or working with existing providers, staff strive to serve as part of an integrated system, assisting families to overcome barriers to needed services and resources.

"Anne" is a 3 year-old girl in foster care. Anne's foster parent brought her to the CCSHCN neurology clinic in her area for seizures and abnormal gait. Through testing arranged by CCSHCN, she was diagnosed and provided needed medication. Following up on other concerns, Anne was quickly seen in cardiology clinic, orthopedic clinic, and started in physical therapy. Due to her multiple needs, CCSHCN initiated monthly visits to the foster home as part of the Medically Fragile Foster Care program, and developed an Individualized Health Plan, which is reviewed regularly with Anne's "team". Having been seen privately by a ENT whose testing showed severe hearing loss in both ears, the hearing aid process was started. CCSHCN's audiologist questioned the results when another child was referred for the same exact hearing loss, which is highly unusual. Repeat testing was completed, and showed normal hearing. Unfitted hearing aids were returned for a full refund and child and foster parent were spared the stress of having the child wear hearing aids that were completely unnecessary

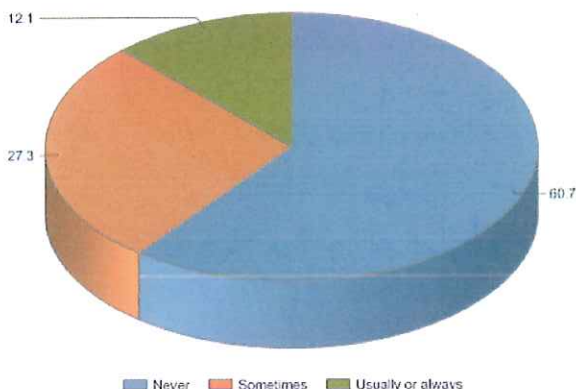
While Anne represents a success story, consider the challenges families of children with special health care needs in Kentucky face in obtaining access to care. As part of CCSHCN's Five-Year Action Plan, the agency continues to develop strategies, coordinate with partners to develop infrastructure, and to assist families through education and navigation in order to facilitate the health and well being of Kentucky's CYSHCN.

<i>Prevalence of Children with Special Health Care Needs (CSHCN), among all children age 0-17</i>	<b>19.5</b>	<b>197,916</b>
	<b>% of CSHCN</b>	<b># of CSHCN</b>
<i>CSHCN whose families cannot easily access community based services</i>	<b>36.2</b>	<b>70,487</b>
<i>CSHCN with any unmet need for specific health care services</i>	<b>21.1</b>	<b>40,447</b>
<i>CSHCN whose families have any unmet need for support services</i>	<b>6.0</b>	<b>11,778</b>
<i>CSHCN needing a referral for specialist care or services and had problems getting it</i>	<b>18.8</b>	<b>12,893</b>
<i>CSHCN without a usual source of care when sick (or who rely on the emergency room)</i>	<b>6.4</b>	<b>12,506</b>
<i>CSHCN without any personal doctor or nurse</i>	<b>5.6</b>	<b>10,934</b>

### Impact on Families with CSHCN

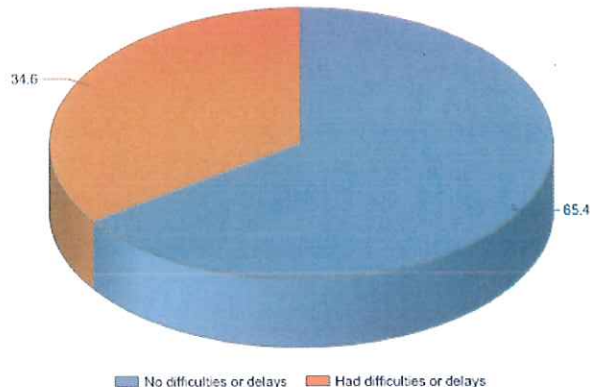
How often parents of CSHCN are frustrated in their efforts to get services for child

CSHCN age 0-17 years  
Kentucky



CSHCN who experienced difficulties or delays getting services

CSHCN age 0-17 years  
Kentucky







# Kentucky Supporting Documents: CYSHCN

---

Commission for Children with Special Health Care Needs

**On the Following Page:**

**Success Story/Data Brief: Insurance**



# Insurance for CSHCN: A Kentucky Story

## Commission for Children with Special Health Care Needs

Financing the care of children and youth with complex health care needs is a special challenge for those families not lawfully present in this country. Those with undocumented status are ineligible for Medicaid, and barred from purchasing coverage under the insurance Marketplace. While rural health centers may provide well care and primary care, and emergency time-limited Medicaid can assist with life-threatening emergencies, few avenues exist for the ongoing care of chronic conditions.

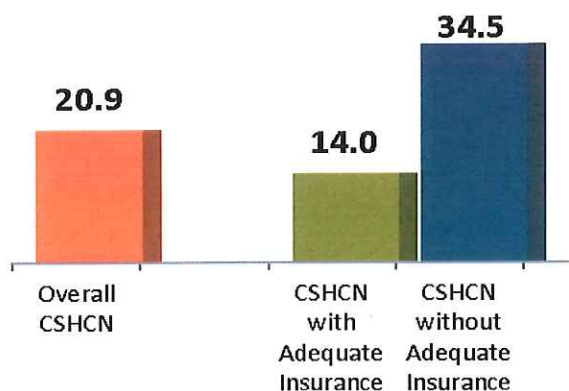
“Hector” is a 19 year-old Kentuckian with Cystic Fibrosis. Though he is prescribed 12 medications and has required multiple surgeries and hospitalizations, Hector has a high school education and the skills to hold a job. Through his employer, Hector has access to group health insurance – rare for a non-citizen. Through care coordination at the Commission for Children with Special Health Care Needs (CCSHCN), Hector now receives insurance case management to ensure adequate coverage for his conditions, and full premium assistance from Patient Services Inc., as well as medication co-pay assistance from Cystic Fibrosis Patient Assistance Foundation – saving over \$140,000 per year between himself and CCSHCN, Kentucky’s Title V agency advocating for the state’s children and youth with special health care needs.

While Hector represents a success story, consider the challenges families of children with special health care needs in Kentucky face in obtaining affordable, consistent coverage. As part of CCSHCN’s Five-Year Action Plan, the agency continues to develop strategies, coordinate with partners to address gaps, and assist families through education and navigation.

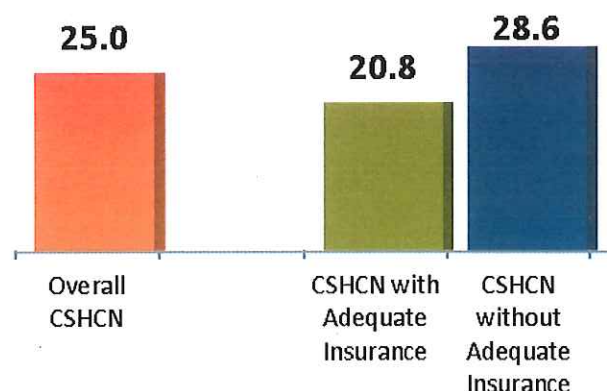
<i>Prevalence of Children with Special Health Care Needs (CSHCN), among all children age 0-17</i>	<b>19.5</b>	<b>197,916</b>
	% of CSHCN	# of CSHCN
<i>Currently insured CSHCN whose insurance is inadequate</i>	<b>29.0</b>	<b>55,061</b>
<i>Impact of CSHCN on the family</i>		
<i>CSHCN whose families pay \$1,000 or more out of pocket in medical expenses per year per child</i>	<b>16.8</b>	<b>32,714</b>
<i>CSHCN whose conditions cause financial problems for the family</i>	<b>20.9</b>	<b>40,588</b>
<i>CSHCN whose families spend 11 or more hours per week providing or coordinating health care</i>	<b>13.7</b>	<b>25,625</b>
<i>CSHCN whose conditions cause family members to cut back or stop working</i>	<b>23.4</b>	<b>45,387</b>

### Impact on Families with CSHCN

Impact on the Family: CSHCN whose conditions cause financial problems for the family



Impact on the Family: CSHCN whose conditions cause family to cut back or stop working







# Kentucky Supporting Documents: CYSHCN

---

Commission for Children with Special Health Care Needs

**On the Following Page:**

**Data Brief: CYSHCN**



# MCH Data Brief

Kentucky Commission for Children with Special Health Care Needs



## Children and Youth with Special Health Care Needs

In Kentucky, almost 200,000 children and youth, or 19.5 percent (compared to 15.1 percent nationwide), have special health care needs. These children have or are at increased risk for chronic physical, developmental, behavioral or emotional conditions and require extensive health services. Since 2001, when the Kentucky percentage was 15.7 percent, the rates have steadily increased. Kentucky currently has the second-highest rate of any state in the nation.<sup>4</sup>

Common conditions include Asthma, Cerebral Palsy, Cleft Lip & Palate, Craniofacial anomalies, Cystic Fibrosis, eye conditions, heart conditions, Hemophilia and other bleeding disorders, Epilepsy and neurological conditions, Spina Bifida, orthopedic conditions, otology or ear/hearing conditions, Autism Spectrum Disorders, and a variety of other health problems, including ADD/ADHD, learning disabilities and mental health issues.

### Key Numbers

97,473: number of Kentucky schoolchildren with disabilities<sup>1</sup>

197,916: number of estimated Kentucky children with special health care needs<sup>2</sup>

299,025: number of estimated Kentucky children reported to have one or more chronic conditions<sup>3</sup>

## Commission for Children with Special Health Care Needs (CCSHCN)

CCSHCN is the state agency responsible for administering federal Title V funds for ensuring the health of children with special health care needs in Kentucky. CCSHCN has been in existence since 1924. The mission of CCSHCN is to enhance the quality of life for Kentucky's children with special health care needs through quality service, leadership, advocacy, education and collaboration. CCSHCN is a department within the Kentucky Cabinet for Health and Family Services.

- ◇ Direct services include ensuring specialty health services (for qualifying conditions) in clinics statewide where care is unavailable or inaccessible
- ◇ Enabling services include arranging transportation, interpreters, care coordination, social work, therapies, and family support programs
- ◇ Population-based services include newborn hearing screening as well as nursing consultation to the foster care system
- ◇ Infrastructure-building services include needs assessment, evaluation, policy development, systems integration, etc.

The chart to the right shows CCSHCN trend data toward Maternal and Child Health Block Grant National and State Performance Measures (NPMs & SPMs) relevant to children and youth with special health care needs (CHSCN), which are as follows:

NPM 2: The % of CHSCN age 0-18 years whose families partner in decision making at all levels and are satisfied with the services they receive

NPM 3: The % of CHSCN age 0-18 years who receive coordinated, ongoing, comprehensive care within a medical home

NPM 4: The % of CHSCN age 0-18 years whose families have adequate private and/or public insurance to pay for the services they need

NPM 5: The % of CHSCN age 0-18 years whose families report that community-based service systems are organized so they can use them easily

NPM 6: The % of youth with special health care needs who received the services necessary to make transitions to all aspects of adult life, including health care, work, and independence

NPM 12: The % of newborns who have been screened for hearing before hospital discharge

SPM 7: The % of children, ages 0-18, receiving CCSHCN services, with a Body Mass Index (BMI) at or above the 85th percentile

SPM 8: The % to which CCSHCN transition action plan is successfully completed and implemented

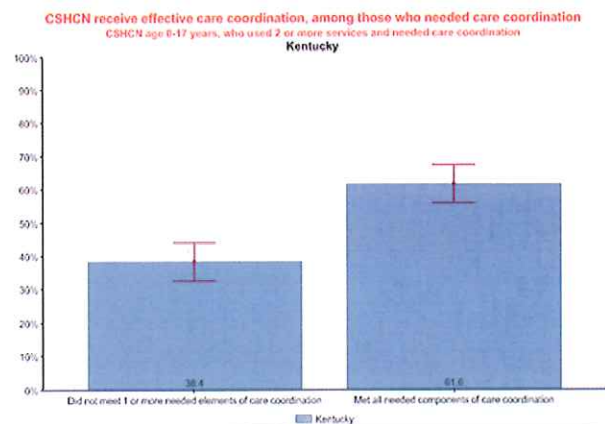
Indicator	2009	2010	2011	2012	2013	5 Yr. Trend
NPM 2	87.8	96.8	97	96.9	96.8	9.0
NPM 3	91.9	93.6	94.5	93.9	94.6	2.7
NPM 4	93.1	96.1	96	96.4	96.8	3.7
NPM 5	95.9	97.1	97.4	96.4	96.3	0.4
NPM 6	61	66.9	61.7	55.2	54.9	-6.1
NPM 12	99.9	96.6	98.1	98.5	96.7	-3.2
SPM 7	NA	33.1	36.7	34.8	35.8	-2.7
SPM 8	NA	46.2	63.5	75	86.5	40.3

	Improvement in indicator
	No definite trend in indicator/unable to denote trend
	Worsening in indicator

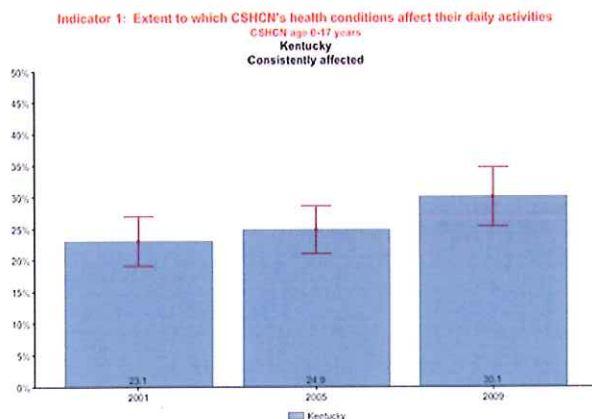


## Measuring System Performance

Children with special health care needs are a diverse group with differing needs, and performance can be difficult to measure. To help evaluate the system, CCSHCN relies on data on services provided to CCSHCN enrollees, comment cards filled out by families in clinics, and the CHSCN Screener, a five-item, parent-reported tool used in two national child health surveys. The chart to the right shows just one metric from a national survey<sup>5</sup>, showing how many Kentucky children who needed care coordination received it.



## Impact of Health Conditions on Children



In addition to the financial impact on families (20.9% of Kentucky families of CSHCN have experienced financial problems due to child's health conditions<sup>6</sup> and 16.8% paid \$1000 or more out-of-pocket in medical expenses for child in past 12 months<sup>7</sup>) special health care needs take a toll on children's functioning in day-to-day life, including (for example) breathing problems, swallowing, circulation, pain, seeing, hearing, taking care of self, coordination, using hands, learning or paying attention, speaking or communicating, feeling anxious or depressed, behavior problems, or making and keeping friends. The chart to the left shows, over three survey periods, that the number who are consistently affected have grown to 30.1% of CHSCN.<sup>8</sup>

## Community Based System of Supports

CCSHCN's goals include collaboration and outreach. By forming initiatives and partnerships with providers, hospitals, state universities, schools, and other agencies, councils, and organizations, CCSHCN is ensuring that more children may be reached and cared for.

Learn more about CCSHCN programs and services by calling (800) 232-1160, or visiting the website: <http://www.chfs.ky.gov/ccshcn>

CCSHCN Regional offices are located in: Ashland, Barbourville, Bowling Green, Elizabethtown, Hazard, Lexington, Louisville, Morehead, Owensboro, Paducah, Prestonsburg, and Somerset.

### Numbers Served by CCSHCN<sup>9</sup>

- ◇ 9220 Clinic visits, including 293 visits via Telemedicine
- ◇ 7541 Audiology visits, including 860 Early Hearing Detection & Intervention ("EHDI") program
- ◇ 2947 Occupational/Physical/Speech Therapy services provided
- ◇ 1463 Home visits to children in foster care placements
- ◇ 2759 Services to families provided by Family to Family Health Information Centers ("F2F")

#### References:

1. Kentucky Department of Education, 2012 Data from School Report Card. Retrieved 5/15/14 from <http://applications.education.ky.gov/src/ProfileByState.aspx>
2. National Survey of Children with Special Health Care Needs. NS-CSHCN 2009/10. Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved 5/20/14 from [www.childhealthdata.org](http://www.childhealthdata.org).
3. National Survey of Children's Health. NSCH 2011/12. Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved 5/20/14 from [www.childhealthdata.org](http://www.childhealthdata.org)
4. National Survey of Children with Special Health Care Needs. NS-CSHCN 2009/10. Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved 5/20/14 from [www.childhealthdata.org](http://www.childhealthdata.org)
5. National Survey of Children with Special Health Care Needs. NS-CSHCN 2009/10. Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved 5/21/14 from [www.childhealthdata.org](http://www.childhealthdata.org)
6. National Survey of Children with Special Health Care Needs. NS-CSHCN 2009/10. Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved 5/21/14 from [www.childhealthdata.org](http://www.childhealthdata.org)
7. National Survey of Children with Special Health Care Needs. NS-CSHCN 2009/10. Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved 5/21/14 from [www.childhealthdata.org](http://www.childhealthdata.org)
8. National Survey of Children with Special Health Care Needs. NS-CSHCN 2009/10. Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved 5/21/14 from [www.childhealthdata.org](http://www.childhealthdata.org)
9. CCSHCN CUP (information system) and agency service data, fiscal year ending 6/30/2014



# Kentucky Supporting Documents: CYSHCN

---

Commission for Children with Special Health Care Needs

**On the Following Page:**

**Results & Process: CYSHCN Needs Assessment**



# Results: 2016-2020 Children and Youth with Special Health Care Needs Five-Year Assessment: Kentucky

## Commission for Children with Special Health Care Needs

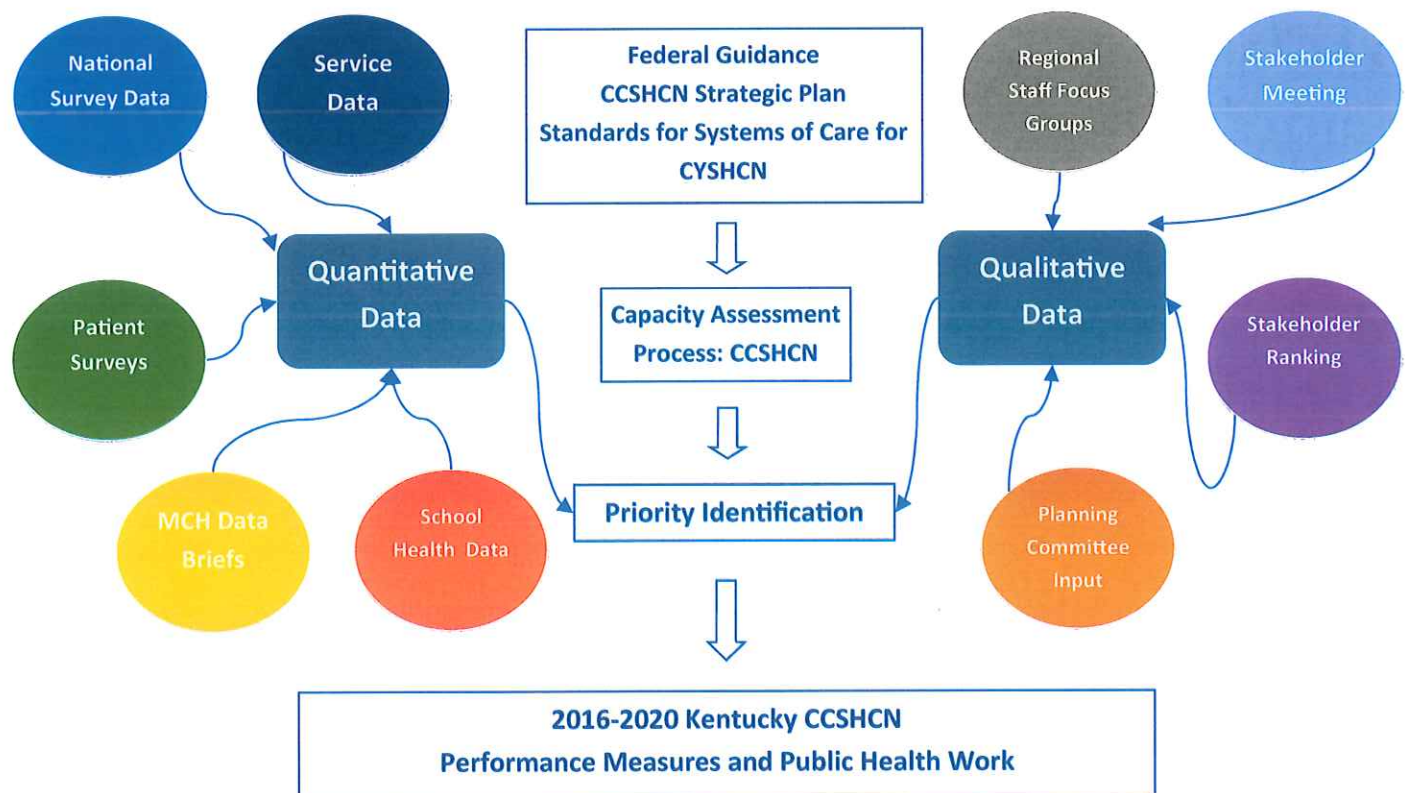


### Overview

Every five years, states are required to submit a Needs Assessment for their Maternal and Child Health Services Title V Block Grant federal funding. The Kentucky Department for Public Health (DPH) is the Kentucky grantee; as a sub-recipient, guidance requires that at least 30% of Title V funding be allocated for services for Children and Youth with Special Health Care Needs (CYSHCN).

### Planning Committee

A team representing staff of both DPH and CSHCN (as well as faculty from the University of Kentucky College of Public Health) is responsible for guiding the development of the needs assessment process and priorities. The process involved the analysis of six population health domains (of which CYSHCN was one) using quantitative and qualitative data as illustrated below. The goal was to examine the data that will drive Maternal and Child Health work for the next five years, with the overall aim of measurable improvement in the health of the population.



## National Survey Data

	2009-2010 NS-CSHCN	2011 NSCH
National Average Rate	15.1%	19.8%
Region IV Average Rate	16.5%	21.1%
<b>Kentucky Rate</b>	<b>19.5%</b>	<b>26.4%</b>
<b>Kentucky Ranking (of 50)</b>	<b>49</b>	<b>50</b>
<b>Kentucky Population Estimate</b>	<b>197,916</b>	<b>268,795</b>

## National Survey Trends

Overall, Kentucky fared well as compared to HRSA Region IV and the nation. Two measures were targeted for improvement:

- Access to community-based services; and
- Transition services

When condition prevalence was examined for these same areas, Kentucky had more children living with:

- Asthma;
- Arthritis;
- ADD or ADHD;
- Behavioral or conduct problems;
- Epilepsy/seizure disorders;
- Heart problems; and
- Cerebral Palsy.

### 9400 Served by CCSHCN—FY 2014

- ◇ Clinic visits (in-person & via Telemedicine)
- ◇ Audiology visits (and Early Hearing program)
- ◇ OT/PT/SLP services
- ◇ Foster home visits
- ◇ Indirect & non face-to-face services provided through partnerships

\*Additionally, Family to Family Health Information Centers served 1587 families, unduplicated

Kentucky fared better than either Region IV or the nation in autism prevalence and blood problems.

## CCSHCN Service Data

CCSHCN reported population improvement in six of eight performance measures (six national, two state-level) examined between the period of 2009 and 2014. The number of infants screened for hearing before hospital discharge revealed a slight decline within this timeframe, due in part to better tracking and an increase in home births. Another measure – tracking childhood BMI – rose slightly in 2013 and 2014, though no discernible trend is evident over the five year period.

## Kentucky Department of Education: School Health Data

To better estimate the prevalence of common chronic conditions (Asthma, Diabetes, and Epilepsy) within the Commonwealth and CCSHCN Regions, staff reviewed school health data. CCSHCN staff was able to estimate the proportion of children affected by county for each condition of interest. The proportion was then applied to the total population of all children (aged 5 – 19 years) residing in each county and estimates about the true prevalence of each condition were extrapolated. These estimates were compared with CCSHCN CUP patient data, allowing CCSHCN leadership to identify gaps, if they existed, at both the state and CCSHCN regional office level. Regional variation data currently under examination.



## Patient Survey Data

Surveys were distributed in health departments as well as CCSHCN clinics. CCSHCN also placed the survey on the agency Facebook page to encourage input. Surveys were also mailed to CCSHCN families whose children were not expected in clinic during survey administration.

3,361 surveys were returned; 813 from CCSHCN families. Statewide and regional CYSHCN reports were generated.

Families said that their greatest concerns for CYSHCN were:

- Making sure families have the ability to receive services;
- Ability to find insurance to pay for care;
- Availability of developmental, social, and emotional screening services;
- Training and support for children with behavioral issues; and
- Finding doctors who can provide care

Priorities of families enrolled in CCSHCN clinical programs varied slightly:

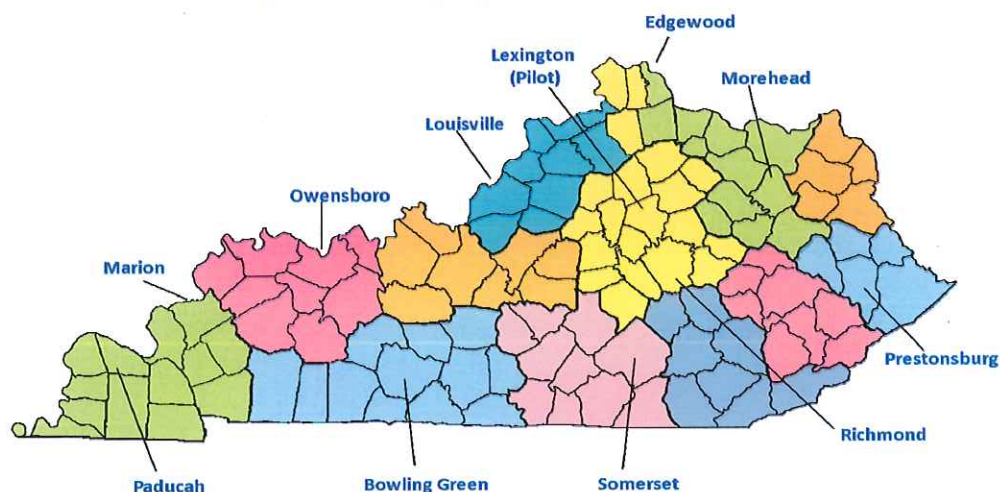
- The need to find insurance moved off the list completely and was replaced by concerns about finding doctors to provide care as the second priority issue.
- Training and support for children with behavioral issues moved to the third priority and the need for early identification of special health care needs was added to the list.

When patient survey responses were examined by Kentucky region, some interesting and statistically significant variations occurred:

- Finding doctors who can provide care was of greater concern in Western Kentucky than in Eastern Kentucky, though the latter is known for its provider shortages;
- Finding insurance to pay for care was more of an issue in Central Kentucky;
- Nearly one quarter of respondents from Eastern Kentucky said that early identification of CYSHCN was a high priority need in their region; and
- The need for transition services was thought to be greater in Eastern Kentucky.

## Regional Focus Groups

At ten focus groups (plus 1 pilot) held throughout Kentucky during 2014, MCH professionals (and parent representatives) discussed issues pertaining to CYSHCN and their families. Access to resources and services was the primary topic of discussion but the impact of substance abuse on families and communities, as well as the increased risk for child abuse, were also highlighted.





## MCH Stakeholder Meeting

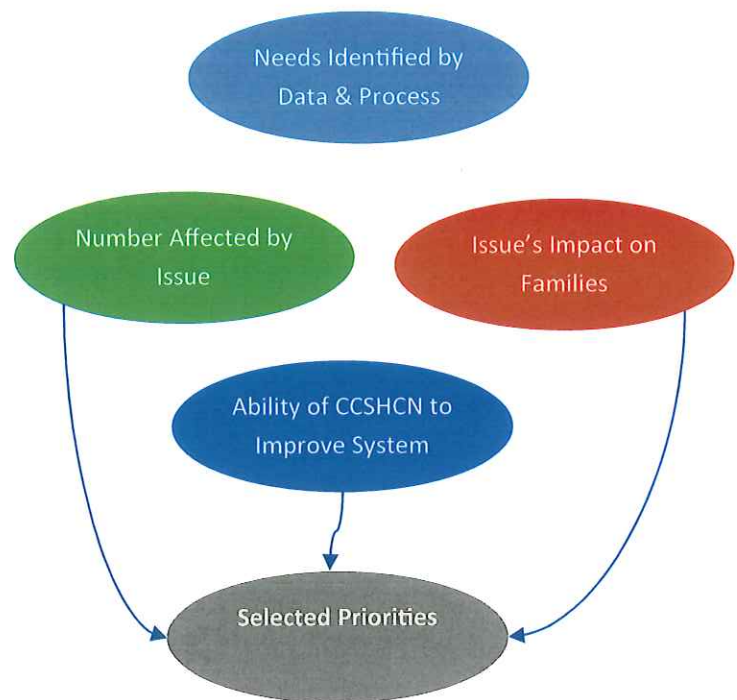
At a November meeting in Frankfort, nearly one hundred partners convened to discuss MCH improvement. Two tables were selected for in-depth exploration and discussion of CYSHCN issues. Tables addressed gaps associated with access to care, provider capacity and supports/resources for families. Stakeholders identified possible solutions and promising practices to these complex issues.

## Alignment with CYSHCN Outcomes

A well-functioning system of services for CYSHCN includes the following, which CSHCN bears in mind in selecting priorities:

- Family Partnership & Satisfaction
- Medical Home
- Transitions Preparation
- Insurance Adequacy
- Early Screening
- Ease of Use of Community Based Services

## Prioritization Process



## Final Selected Priorities

**Easy access to care and services** – including:

- (1) Access to medical and specialty care,
- (2) Assuring the availability of provider networks to reach CYSHCN; and
- (3) Developing and promoting an easy to access system of supports and resources for CYSHCN and their families.

**Improvement of transitions services**

**Adequate insurance to pay for needed services**

**Improvement of data capacity**

## Next Steps

In partnership with DPH and other stakeholders, and in accordance with national best practice standards and the agency strategic plan, CSHCN will be developing Evidence-Based and/or Evidence-Informed Measures will to assist in achieving success in each of these priority areas. Progress or lack of progress will be measured through an annual scoring of Kentucky's specific implementation plans.

## For More Information:

Mike Weinrauch—[mike.weinrauch@ky.gov](mailto:mike.weinrauch@ky.gov) (800) 232-1160, ext. 2026

Learn more about CSHCN programs and services by calling (800) 232-1160, or visiting the website:  
<http://www.chfs.ky.gov/ccshcn>





# Kentucky Supporting Documents: CYSHCN

---

Commission for Children with Special Health Care Needs

**On the Following Page:**

**CCSHCN Strategic Plan Overview**

*CCSHCN will seek collaboration with service providers, hospitals, schools and other groups to improve our service and efficiency.*

*CCSHCN will seek collaboration with service providers, hospitals, schools and other groups to improve our service and efficiency.*

Action Item	Assigned to:	Target Date	Products	Due By	Person Responsible
1.1 Identify and seek partnerships (Focus group appointed by Exec. Dir.)	Focus group and Executive Director	10/01/13	Database of contacts and results	10/01/13	Executive Director
1.2 Hold State Wide "Open Houses" (2 East, 2 West) for community based Service Partners, Providers and their Families	Nurse Administrators	Summer 2014	<p>Create statewide listing of Community Based Service Partners, Providers and their families. (a)</p> <p>Identify Open House locations (b)</p> <p>Develop media materials and invitations to Open Houses (c)</p> <p>Document attendees at Open Houses (d)</p> <p>Evaluate effectiveness of Open Houses (e)</p> <p>Update statewide listing (f)</p>	<p>10/01/13</p> <p>04/01/2014</p> <p>04/01/2014</p> <p>07/01/2014</p> <p>10/01/2014</p> <p>10/01/2014</p>	<p>Nurse Service Administrators/ East and West</p>
1.3 Ask Community Based Service Partners, Providers what resources/information they need from us to give to families/patients	Nurse Administrators/ Social Workers	Fall 2013 – Spring 2014	<p>Develop survey (a)</p> <p>Develop information materials/packets (b)</p> <p>Disseminate information and document recipients (c)</p>	<p>10/01/2013</p> <p>04/01/2014</p> <p>07/01/2014</p>	<p>Nurse Service Administrators/ East and West</p>



## Goal #2: Marketing and Outreach

*CCSHCN will create a communications and marketing plan to address the lack of awareness of our services throughout the state and within state government.*

Action Item	Assigned to:	Target Date	Products	Due By	Person Responsible
2.1 Develop a communication and marketing plan	CCSHCN Leadership CHFS Communication division	July 1, 2013 – September 30, 2013 with implementation on 10/1/2013 (reviewed annually)	Communication and Marketing Plan (a)	10/1/2013	Health Information & Technology Branch Manager
		Annual review	Evaluation (b)	10/1/2014	
2.2 Mobilize the PAC and YAC to raise awareness of CCSHCN programs and services through social media and other outlets	Chair of PAC  Chair of YAC  Transition Administrator and PC's  Information Officer	9/1/2013 – ongoing	Create and conduct survey on member awareness (a)  Develop membership training plan (b)  Conduct membership training sessions (c)  Develop PAC & YAC brochures (d)  Create media plans (e)  Develop promotion materials, PSA's (f)  Identify opportunities for members to deliver content (g)	10/1/2013  1/1/2014  4/1/2014  7/1/2014  7/1/2014  7/1/2014  10/1/2014	Transition Administrator

Action Item	Assigned to:	Target Date	Products	Due By	Person Responsible
2.3 Increase visibility of CSHCN through ensuring availability of CSHCN literature by providing contact information in Birthday Bags to all newborns in the State of KY	Nurse Service Administrator East/West Nurse Administrators Hospital Representatives E.H.D.I.	9/1/2013 - ongoing	Identify CSHCN literature for bags (a)  Collect baseline data on # of newborns, # of bags and # of referrals (b)	10/1/2013  10/1/2013	Nurse Service Administrators/ East and West
			Collect data on # of newborns, # of bags and # of referrals (c)	10/1/2014	



## Goal #3: Operational Improvement

CCSHCN will evaluate all practices and identify necessary areas for improvement.

Action Item:	Assigned to:	Target Date:	Products	Due By	Person Responsible
3.1 Intake/Eligibility: Simplify and standardize application materials and process(es) used by agency, including the development and implementation of an electronic application.	Intake/Administration	7/1/2013 – 9/1/2014	Develop modular forms for state wide use designed to: (1) capture accurate information as needed for multiple agency programs, and (2) be applicant friendly (e.g., visually attractive, concise, clearly understandable, in English and Spanish, and easy to complete). (a)	Create by 7/1/2013	Intake & Eligibility Branch Manager
			Implement (b)	9/1/2013-9/30/2013	
			Monitor effectiveness and identify needed adjustments (c)	9/1/2013-12/30/2012	
			Develop and implement an electronic application (d)	1/1/2014-9/30/2014	Health Information & Technology Branch Manager
3.2 Evaluate clinic process for efficiency: improved services, appropriate scheduling, reduce no shows, clinic patient flow, all documentation of clinic services provided.	Nurse Administrator District Offices Providers	7/1/2013 – 6/30/2016	Develop rubric for evaluating Efficiency (a)	10/1/2013	
			Evaluate efficiency (b)	10/1/2014	
			Evaluation efficiency (c)	10/1/2015	
			Evaluate efficiency (d)	10/1/2016	
3.3 Evaluate service needs and identify opportunities to build infrastructure and expand population-based services to meet the identified needs.	Director of Nursing Clinical Branch Managers Nurse Administrators	7/1/2013 – 6/30/2016	Identify infrastructure Opportunities (a) Identify additional population based services (b)	1/1/2014 1/1/2014	

## Goal #4: Tele-health

*CCHCN will develop and implement a plan for providing at least three agency services using tele-health technology by 12/31/2015, in order to better utilize provider resources and improve the quality and timeliness of service delivery to patients throughout Kentucky.*

Action Item:	Assigned to:	Target Date:	Products	Due By	Responsible Person
4.1 Develop Tele-health Team to collaborate with in-state experts and allies.  Tasks include: communicating with families and patients, consult experts (in-state, out-of-state, others), get buy-in from providers (by 12/13).	Deputy Director Executive team	July, 2013	Develop communication plan and materials	7/1/2013	Deputy Director
4.2 Evaluate all services to determine best three for initial Tele-health trials	Tele-health team Executive team	12/13/2013	Develop rubric for evaluating services (a)  Identify training needs (b)	1/1/2014  1/1/2014	
4.3 Determine cost and equipment needs	Deputy Director Tele-health team	January 2014	Itemize equipment and costs	1/1/2014	
4.4 Test process and proposal	Deputy Director Tele-health team	March 2013	Develop implementation guide for trials (a)  Develop forms (b)	4/1/2014  4/1/2014	

Action Item:	Assigned to:	Target Date:	Products	Due By	Responsible Person
4.5 Implement Tele-health trials (3 services)	Deputy Director Tele-health team	June 2014	Identify criteria for measuring success	7/1/2014	
4.6 Evaluate effectiveness of trials	Deputy Director Tele-health team	December 2014	Feedback from patients and providers (a) Data measuring success (b)	1/1/2015 1/1/2015	
4.7 Roll out broader Tele-health services	Deputy Director Tele-health team	December 2015	Complete 4.2 and 4.3	1/1/2016	



## Goal #5: Provider Recruitment/Retention

*CCSHCN will recruit/retain physicians to meet service delivery needs as determined by the Executive Committee and Board by June 2016 and thereafter.*

Action Item:	Assigned to:	Target Date:	Products	Due By	Person Responsible
5.1 Complete written recruitment process/procedure for physicians	Clinical and Augmentative Division Director and sub-committee of stakeholders	6/30/2014	Identify physicians  Draft recruitment process for physicians  Final recruitment process for physicians	07/1/2013  1/1/2014  6/30/2014	Clinical & Augmentative Division Director
5.2 Complete written externship/fellowship/training process/procedure for physicians	Executive Director  Medical Director  Deputy Director,  Committee of Stakeholders	6/30/2014	Identify training programs physicians (a)  Draft training process for physicians (b)  Final training process for physicians (c)	7/1/2014  4/1/2014  7/1/2014	Medical Director
5.3 Identify financial incentives for physicians: loan forgiveness, contractual scholarships (pay an amount of tuition for each year of service), negotiated reimbursement rates (pay per hour/we cover overhead, billing, preauthorization), identify budget and grant money for all above	Financial and Administrative Division Director,  Committee of Stakeholders	6/30/2014	Final report on incentives (a)  Final report on budget and grant money (b)	7/1/2014  7/1/2014	Financial and Administrative Division Director



# Kentucky Supporting Documents: CYSHCN

---

Commission for Children with Special Health Care Needs

**On the Following Page:**

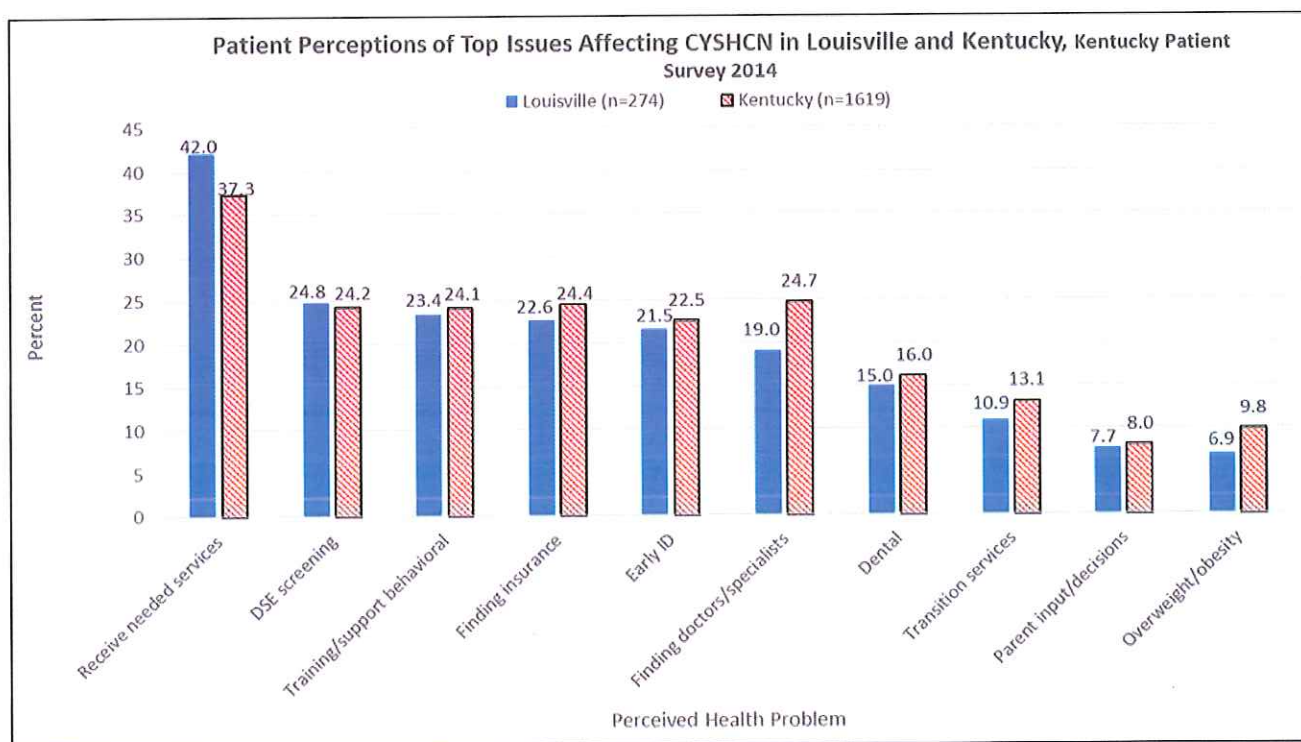
**Example of Regional Report—Patient Survey Data**

## Louisville CSHCN Overview

### Introduction

The 2014 Maternal and Child Health Patient Survey was provided to Local Health Department (LHD) and Commission for Children with Special Health Care Needs (CCSHCN) patients during the month of May 2014 to identify public health issues of concern across the Commonwealth. A total of 3361 surveys were returned from Pikeville to Paducah. This individualized summary report, created for each CCSHCN region, represents a portion of this total (n = 1619). The report was created by combining the responses of families *currently enrolled* in CCSHCN services with those LHD patients who indicated that there was a child in their home with special health care needs. The Kentucky Department for Public Health and the Kentucky Commission for Children with Special Health Care Needs would like to recognize all who participated in the distribution of this survey as well as the important contributions provided by respondents.

**In the Louisville CCSHCN and LHD service area**, a total of 274 surveys were returned, 161 of which represented CCSHCN families and 113 from LHD patients. All respondents were asked to list perceived health problems they believe often affect children and youth with special health care needs.



### Health Problem Topics Key – Problems that affect Children and Youth with Special Health Care Needs (CYSHCN)

- Making sure that families are able to receive needed services (Receive needed services)
- Developmental, social, emotional screening (DSE Screening)
- Training and support for children with behavior issues (Training/support behavioral)
- Finding insurance to pay for needed services (Finding insurance)
- Early identification of special health care needs (Early ID)
- Finding doctors who can provide care (Finding doctors/specialists)
- Dental health
- Receiving services necessary to move into adult life (Transition services)
- Making sure that parents help to make decisions (Parent input/decisions)

### Other perceived problems concerning CYSHCN from Louisville respondents:

*"Finding good dentist more physical therapy [sic]"*  
*"Inadequate understanding by educators"*  
*"Interaction with normal kids is harder as she gets older and her disabilities are more noticeable"*  
*"Lack of funding for adaptive and transportation [sic] equipment"*  
*"Parents not wanting to work with them lazy [sic]"*  
*"Transportation/gas money vehicle [sic]"*



## Results – Kentucky Overview (n=1619)

When asked about needs for Kentucky CYSHCN, participants said that their greatest concerns were (in order of need):

1. The ability of families to receive needed services
2. Finding doctors who could provide care
3. Finding insurance to pay for needed services
4. Developmental, social, & emotional screening
5. Training & support for children with behavioral issues

Variations were observed when examining patient survey responses by Kentucky Region (Eastern, Central, and Western KY). All three regions ranked the problem of *making sure that families are able to receive needed services* as the highest priority. Second highest was *finding doctors to provide care* in both Eastern (26.3%) and Western (31.3%) Kentucky. This issue was ranked in sixth place (20.1%) in Central Kentucky.

## Health Care Needs

Two hundred forty-one (88%) out of 274 respondents from the **Louisville CSHCN** region reported<sup>1</sup> that a child (or children) in their family had one or more of the following health care needs: **Behavioral problems** (52.7%); **Chronic health conditions** (52.3%); **Developmental disabilities** (36.1%); or **Emotional problems** (32.8%). Just over half of these families (52.3%) reported a child with a single condition while just over one quarter (28.2%) reported a child with conditions in two categories, and an additional 19.5% said the child had health issues in three or more categories. Of those reporting above,

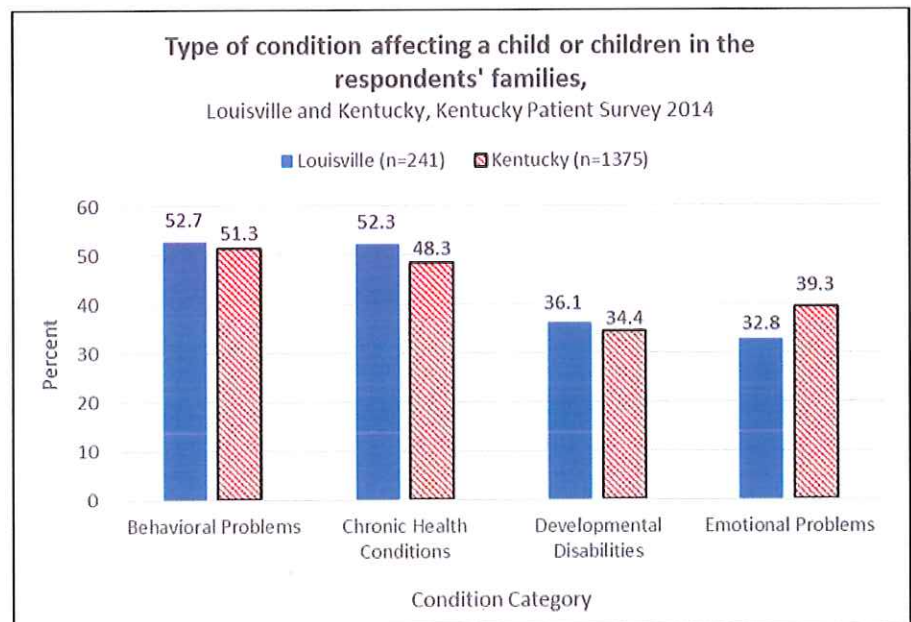
128 were currently enrolled in CSHCN services while 113 were LHD patients from the CSHCN Louisville region.

## Age of Diagnosis

When asked at what age their child was diagnosed, 41% said that the child had been diagnosed<sup>2</sup> by or before the age of two years. Of those who reported early diagnosis, the majority (71%) were current CSHCN enrollees. Twenty-three percent (22.7%) of children were reported to have been diagnosed between the ages of 2-4 years with 36.2% diagnosed after the age of 4 years.

## Resources for Families

Eighty-two percent (82%) of CSHCN families and 53% of LHD patients from the Louisville region said that they knew about services<sup>3</sup> offered by CSHCN. When asked if they would use peer<sup>4</sup> support groups if available, 67% of LHD patients said that they would while 77% of CSHCN families said that they would use these services.



<sup>1</sup> Respondents could pick one or more categories for this question and may be reporting about one child or multiple children in their response.

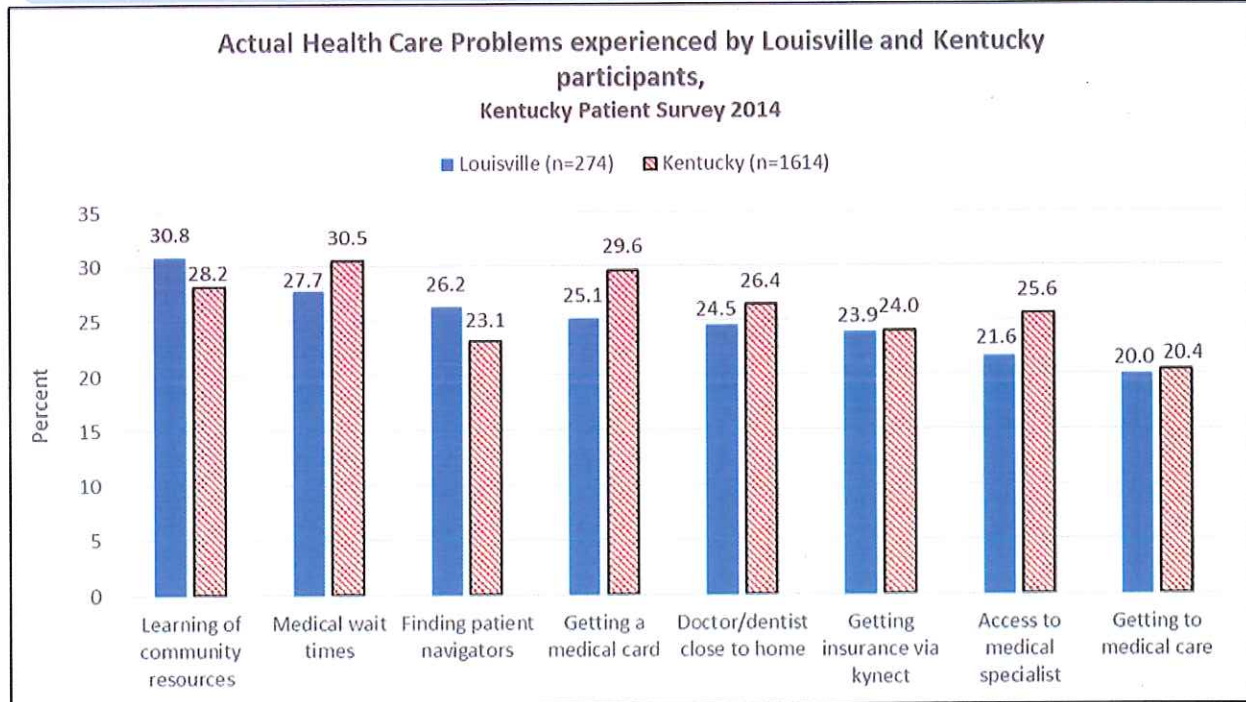
<sup>2</sup> Respondents could pick one or more categories for this question and may be reporting about one diagnosis or multiple diagnoses in their response (n=229).

<sup>3</sup> A total of two hundred thirty-four (n=234) individuals completed this question (services)

<sup>4</sup> A total of one hundred eighty-one (n=181) individuals completed this question (peer support groups).



Areas in which 15.0% or more of the Louisville participants experienced a problem getting the service.



### Community programs, services, & resources Louisville respondents would like to suggest

#### Specialist medical and dental care

*"More specialists who take all insurance" "Speech and occupational therapist for special needs child in the south end of Louisville, not just the east end. More schools that serve special needs children [sic]," "Dental," "Mental health is a huge deficit, especially since most places do not accept insurance," "Equine (hippotherapy) for child with sensory processing disorder. Insurance currently will not cover this (Passport)," "Respite for special needs childcare, transition services for young adult with autism"*

#### Peer support

*"We need support groups where we live!!!" "Support group especially for first time mothers to be able to help with questions and concerns to show up along the way! [sic]"*

#### Social activities

*"I am aware of the one's we use, but not all of the resources. We are very grateful and blessed and thank you for what you do for us.[Child] is just at the age she's wanting to get involved in sports, activities and with her c/p MMD I don't know where to start, PH #s or locations do you have a list or access for that [sic]," "Are these summer camp programs for lake my child with cost efficiency income in mind [sic]," "More opportunities for my 9-year-old daughter with developmental disabilities to participate in her community and be with peers. We would love to see a special needs soccer group, cheerleading group or social group. She does not have autism or Down Syndrome, and most of the programs in my community are for children with those specific diagnoses. Very frustrating. Like her disability is not that bad and she doesn't need special services, but she only has a an IQ in the low 50s [sic]," "We would love to see more after school care for young adults w/special needs and more adult support groups for parents of these children"*

#### Environment

*"Housing," "Section 8," "Section 8 housing," "Rent help electric help GED program," Insurance for myself," "Breastfeeding, car seat programs, domestic violence programs, baby bed program, aids screenings[sic]," "Travel reimbursement mentoring for various reason-health behavior, in home therapy that is not attached to CS behavior management," "Child friendly public transport Tarc buses are difficult with small children especially single mothers with multiple children[sic]," "Hart supported living, habitat for humanities, wheelchair accessible transportation"*

#### Other

*"Autism adhd [sic]," "Resources on ASD," "I have a son with problem he don't have develop left ear. May can you help find a way for help him (please Spanish speaker) [sic]," "Parents taking responsibility for their kids"*



**Demographics**

- The majority (69.0%) of Louisville respondents were white, 23.4% were black/African American, 1.1% were Asian/Pacific Islander, and 1.5% selected "other" as their race. Fourteen respondents (5.1%) did not provide information on race.
- Eighty-four (84.3%) of Louisville respondents were non-Hispanic, compared to 7.3% who were Hispanic, and twenty-three respondents (8.4%) did not provide information on ethnicity.
- The majority of Louisville respondents (41.2%) were single, 37.6% were married, 10.9% were single living with a partner, and 5.5% had some other living arrangement. Thirteen (4.7%) respondents did not provide information on marital status.

**Methods**

In order to establish the CCSHCN service area in which the respondent lived, the survey gathered information on the county in which participants lived and the clinic they were visiting. Respondents were next asked to pick two health problems they believe affect children with special health care needs. This individualized summary report includes information regarding perceived health problems affecting children and youth with special health care needs (perceived health problems of women, babies and children, and teenagers have been excluded from this summary).

In order to establish whether a child/children or youth with special health care needs resided within the participants' home, the health care needs section of the survey asked participants if any children (ages 0-21) in their family had health problems from the categories of 1) chronic health conditions, 2) developmental disabilities, 3) behavioral problems, and/or 4) emotional problems, and participants were asked to select all health conditions that applied. Participants with a child in their family with any health condition selected were asked if they were aware of the services provided by the CCSHCN, in which age group the child received diagnosis, and if participants would use parent or youth peer support groups if available.

Participants were given a list of health care services often needed by women and their families, and were asked for each of 14 services to circle "Y" for "yes" if they or someone they knew faced a problem getting this service, and "N" for "no" if they or someone they knew had not faced a problem in getting the service. Participants selected N/A if they had not needed the service. Participants were asked to list any additional community programs, services, or resources they would like to have for their family. Demographic information on respondent age, race, ethnicity, and marital status was gathered.

Descriptive epidemiology and frequency counts were used to determine the total number and percentage of respondents who completed each question for both the CCSHCN service area and the total of Kentucky respondents.

*For more information contact:*

**Mike Weinrauch**

Health Program Administrator

Commission for Children with Special Health Care Needs

310 Whittington Parkway, Suite 200

Louisville, KY 40222

[\(502\) 429-4430, ext. 2026](tel:(502)429-4430)

[\(800\) 232-1160, ext. 2026](tel:(800)232-1160)

[\(502\) 429-4430, fax](tel:(502)429-4430)

[mike.weinrauch@ky.gov](mailto:mike.weinrauch@ky.gov)

CCSHCN Regional Office	CCSHCN Families	LHD Patients	Total
Ashland	30	7	37
Barbourville	43	25	68
Bowling Green	74	7	81
Elizabethtown	52	19	71
Hazard	58	46	104
Lexington	135	201	336
Louisville	161	113	274
Morehead	49	45	94
Owensboro	76	70	146
Paducah	64	124	188
Prestonsburg	39	99	138
Somerset	24	50	74
Missing	8	0	8
<b>Total</b>	<b>813</b>	<b>806</b>	<b>1619</b>



# Kentucky Supporting Documents: CYSHCN

---

Commission for Children with Special Health Care Needs

**On the Following Page:**

**Graduate Student in Epidemiology Analysis of NS-  
CSHCN & NSCH**

# Kentucky Children with Special Health Care Needs

The Commission for Children with Special Health Care Needs



Caitlin Dunworth, B.S. Virginia Tech, 2011  
MPH Candidate, 2015, University of Kentucky College of Public Health  
HRSA Graduate Student Epidemiology Intern Program  
Commission for Children with Special Health Care Needs-Louisville, KY

## Objectives

- Learn about the two data sources, the NS-CSHCN and NSCH
- Learn how CSHCN are identified according to Screener criteria
- Understand state, regional, and national prevalence level breakdowns
- Look at inequities between CSHCN and non-CSHCN
- Read comments from CCHCN clients responding to the question, "Please list any community programs, services, or resources you would like to have for your family"

## Children with Special Health Care Needs

- Children "who have or are at risk for a chronic physical, developmental, behavioral, or emotional conditions and who require health and related services beyond the type or amount required by children generally"
- This definition
  - Is broad
  - Inclusive
  - Considers the consequences of a condition or conditions, not merely the diagnosis
  - Does not include children at risk for a special health care need or difficulty
- Recognizes more CSHCN than the Commission serves



## The 2009-2010 National Survey of Children with Special Health Care Needs



- NS-CSHCN
- Conducted in 2001, 2005-2006, and 2009-2010
- Random sample National Telephone Survey of parent/caretaker
- Sponsored by
  - HRSA MCH, CDC National Center for Health Statistics
  - CAHMI
- Data Resource Center; survey data available at [childhealthdata.org](http://childhealthdata.org)

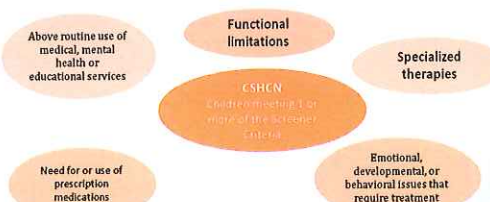
## The 2009/2010 NS-CSHCN

### Key Purposes

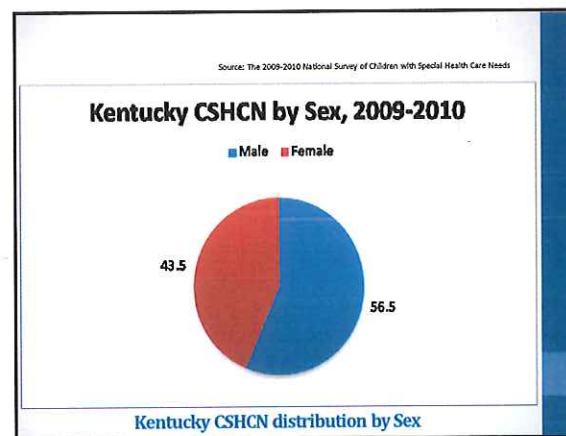
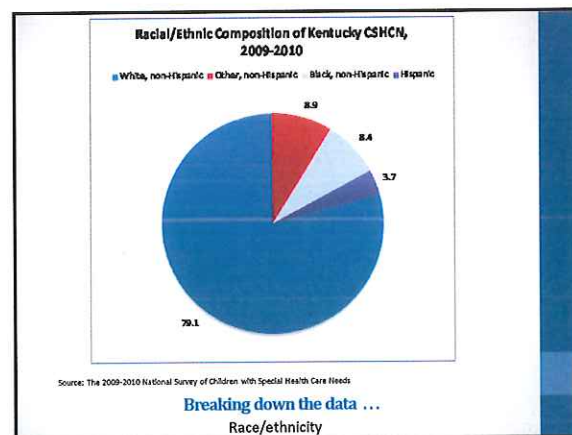
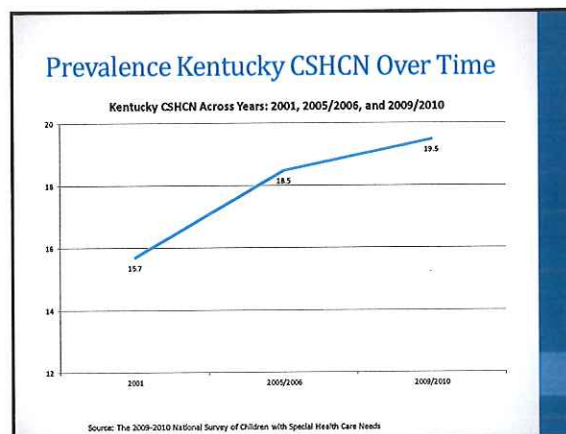
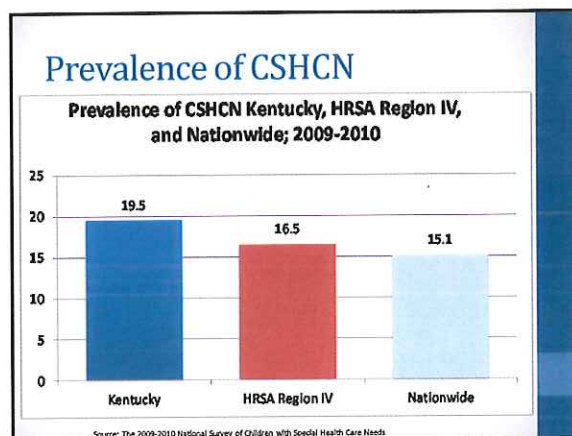
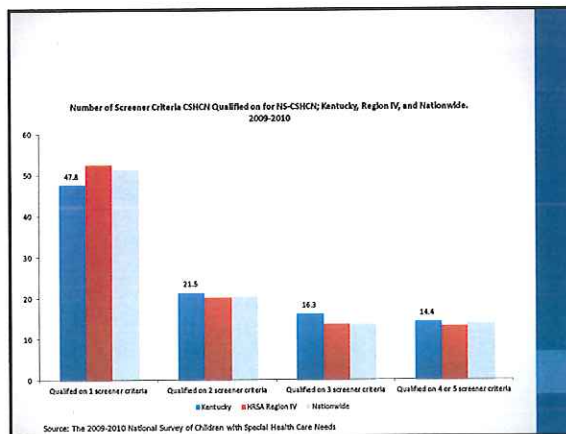
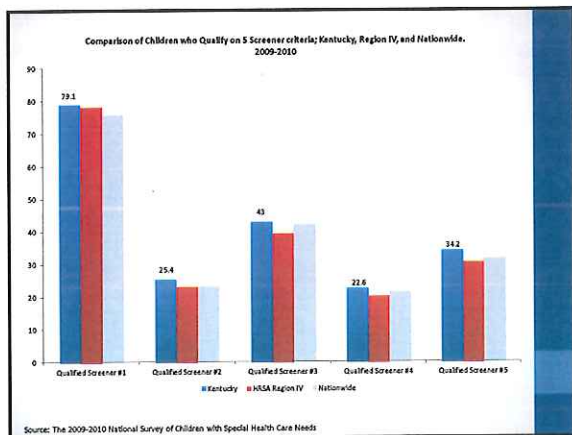
- To estimate state level prevalence for a number of child health indicators, particularly for those pertaining to the health and well-being of children and youth with special health care needs
- To help guide policymakers, key stakeholders, advocates, researchers, and health care providers
- Provide baseline estimates for state performance measures and state-level needs assessment
- To complement the National Survey of Children's Health

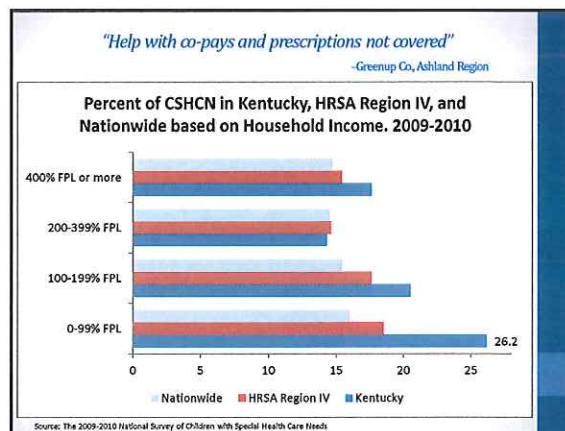
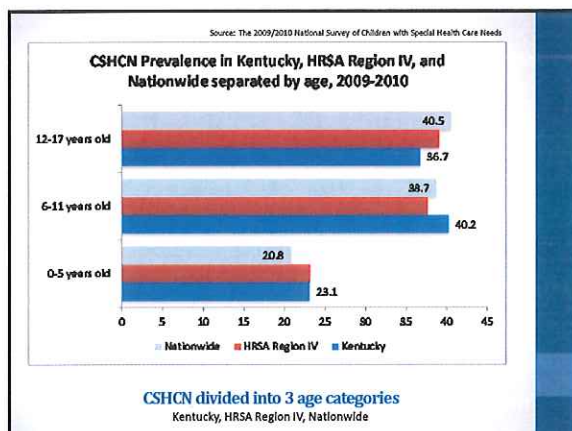
## Identifying CSHCN

- NS-CSHCN uses the CSHCN Screener, a validated measurement tool with 5 screener criteria
- The CSHCN Screener asks parents about the health consequences of the following due to the child's health condition lasting or expected to last for a period of 12 months or longer:









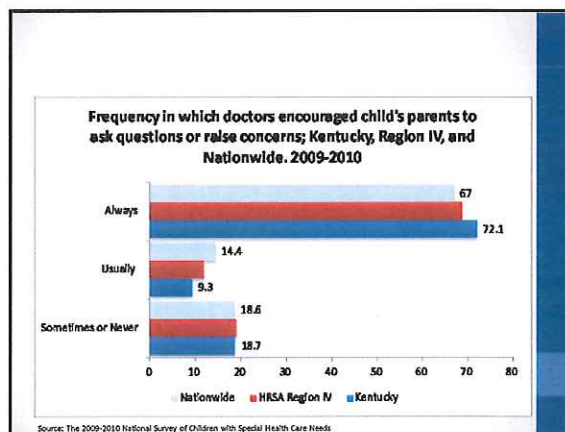
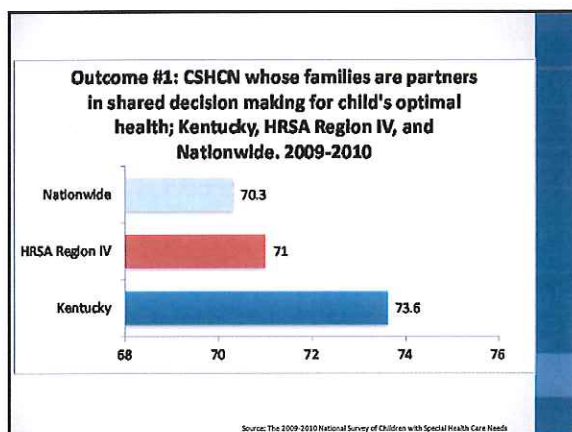
**Core Outcomes:**  
**Measuring Performance**

- Identified by HRSA's Maternal and Child Health Bureau
- Help give us a way to measure family-centered, coordinated, community-based care for CSHCN

- Families partner in decision making
- CSHCN receive coordinated, ongoing, comprehensive care within a medical home
- Families have adequate private and/or public insurance for needed services
- Children screened early and continuously
- Community-based services are organized so families can easily use them
- Youth with SHCN receive necessary services to make transitions to aspects of adult life, including adult health care, work, and independence

**Outcome #1: CSHCN whose families are partners in shared decision-making for optimal health**

- Child's doctors discussed range of healthcare/ treatment options
- Child's doctors encourage parents to ask questions or raise concerns
- Child's doctors make it easy for parents to ask questions or raise concerns
- Child's doctors respect treatment choices

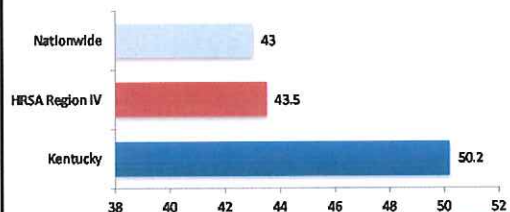


### Outcome #2: CSHCN have a medical home

- Usual source(s) for sick and well care
- Personal doctor or nurse
- No problems obtaining referrals
- Receives family centered care
- Receives effective care coordination

### Outcome #2: Medical Home

#### Outcome #2: CSHCN who receive coordinated, ongoing, comprehensive care within a medical home; Kentucky and HRSA Region IV, 2009-2010



Source: The 2009-2010 National Survey of Children with Special Health Care Needs

### The Importance of having a Medical Home

- Collaboration between providers and the child and family that is ongoing, accessible, comprehensive, coordinated, integrated, and culturally effective
- Providing care in a medical home is thought to reduce the overall total cost of care
- Should provide:
  - Preventive services
  - Immunizations
  - Growth & developmental assessments
  - Screening
  - Health care supervision
  - Patient & family counseling about health and psychosocial issues
  - Care Coordination & Planning

#### Medical homes improve outcomes for CSHCN

- Care is more clinically effective, timelier, and more family centered when delivered in a medical home

### Family Centered Care

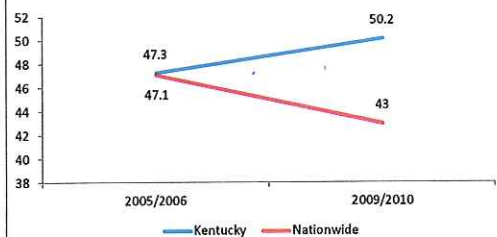
- A subcomponent of medical home core outcome #2
- Child's doctors spend enough time with him/her
- Child's doctors listen carefully to his/her parents
- Child's doctors are sensitive to family custom and values
- Child's doctors provided information specific to the child's health
- Child's doctor help family feel like partner in care

#### Children live within the context of families

- Family centered care—process to ensure the organization and delivery of services meet the social, developmental, and emotional needs of children; and that the strengths and priorities of the families are integrated into all aspects of the service system

*"Family resource point of contact to find out about available therapies & supports in our community"*  
—Warren Co., Bowling Green Region

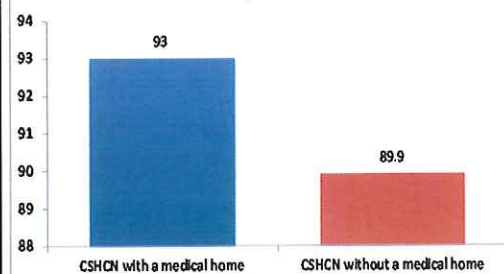
#### Outcome #2 Successfully Achieved; Kentucky and Nationwide over time, 2005/2006 through 2009/2010.



Source: The 2009-2010 National Survey of Children with Special Health Care Needs

*"If we had insurance, none of these would be a problem"*  
—Whitley Co., Barbourville Region

#### Kentucky CSHCN consistently insured during the past 12 months; 2009-2010.



Source: The 2009-2010 National Survey of Children with Special Health Care Needs

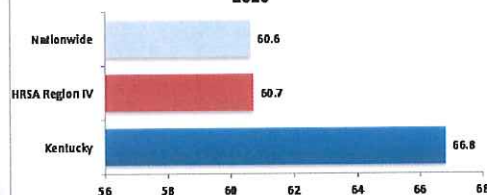


### Outcome #3: Consistent & Adequate Health Insurance

- Currently insured
- No gaps in coverage during the past 12 months
- Adequacy of current insurance
  - Current health insurance benefits meet child's needs
  - Uncovered costs are reasonable
  - Health insurance allows child to see needed providers

### Outcome #3: Insurance Adequacy

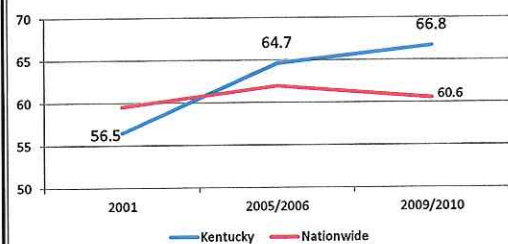
**Outcome #3: CSHCN whose families have consistent and adequate private and/or public insurance to pay for the services they need; Kentucky, HRSA Region IV, and Nationwide, 2009-2010**



Source: The 2009-2010 National Survey of Children with Special Health Care Needs

### Insurance Outcome Over Time

**Outcome #3 Successfully Achieved Over time; Kentucky and Nationwide, 2001 through 2009/2010.**



Source: The 2009-2010 National Survey of Children with Special Health Care Needs

### What community members say...

*"Mental health is a huge deficit, especially since most places do not accept insurance"*  
-Jefferson Co., Louisville Region

*"Dermatologist for my child there is not one who takes Coventry care insurance"*  
-Christian Co., Bowling Green Region

*"Medicaid provider compensation to attract good providers"*  
-Franklin Co., Lexington Region

*"More specialist who take all insurance"*  
-Jefferson Co., Louisville Region

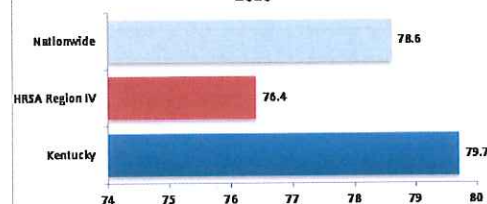
*"Our Comp Care used to provide a lot of services for the community, but they quit those services and I don't understand why or how they could do that"*  
-Anderson Co., Lexington Region

### Outcome #4: Early & Continuous Screening

- Well child check-up in the past 12 months
- Preventive dental visits in the past 12 months

### Outcome #4: Early & Continuous Screening

**Outcome #4: CSHCN who are screened early and continuously for special health care needs; Kentucky, HRSA Region IV, and Nationwide, 2009-2010**



Source: The 2009-2010 National Survey of Children with Special Health Care Needs

## What our community is saying...

*"Developmental screening"*  
-Warren Co., Bowling Green Region

*"Developmental evaluations and therapies for autism such as ABA (applied behavior analysis)"*  
-Letcher Co., Hazard Region

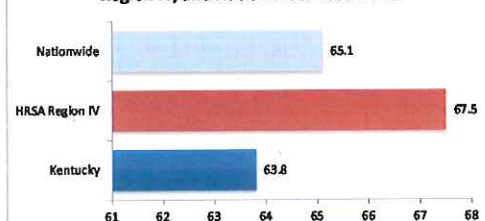
*"To be able to find out what is wrong with our son"*  
-Fulton Co., Paducah Region

## Outcome #5: Access to Community Based Services

- Difficulties or delays receiving services
  - Difficulties or delays due to eligibility
  - Difficulties or delays due to availability
  - Difficulties or delays due to problems getting appointments
  - Difficulties or delays due to cost
  - Difficulties or delays due to trouble getting needed information
  - Difficulties or delays for any other reason
- Parental frustration in getting services for child

## Outcome #5: Access to Community Based Services

**Outcome #5: CSHCN who can easily access community based services; Kentucky, HRSA Region IV, and Nationwide. 2009-2010**



Source: The 2009-2010 National Survey of Children with Special Health Care Needs

## What our community is saying...

*"More importantly education about the Michelle P Wavier offered to families with special needs"*  
-Hardin Co., Elizabethtown Region

*"Michele waiver"*  
-Warren Co., Bowling Green Region

*"There needs to be some specialist in the area. Most of the time you have to travel to Louisville, Lexington, Paducah or Nashville to see a specialist"*  
-Calloway Co., Paducah Region

*"Child friendly public transport Tarc buses are difficult with small children especially single mothers with multiple children"*  
-Jefferson Co., Louisville Region

*"Medical covered transportation"*  
-Floyd Co., Prestonsburg Region

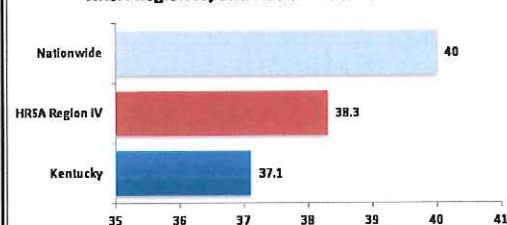
*"Behavioral health facility that will take a child with autism"*  
-Christian Co., Bowling Green Region

## Outcome #6: Transition to Adulthood

- Anticipatory guidance for transition to adult health care, CSHCN age 12-17 years
  - Discussed shift to adult health care providers, if needed
  - Discussed changing health needs as youth becomes an adult, if needed
  - Discussed health insurance as youth becomes an adult, as needed
- Child's doctors encourage self management skills

## Outcome #6: Transitions to Adulthood

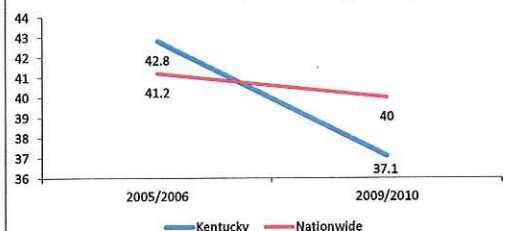
**Outcome #6: CSHCN youth receive services needed for transition to adulthood; Kentucky, HRSA Region IV, and Nationwide. 2009-2010**



Source: The 2009-2010 National Survey of Children with Special Health Care Needs

## Transition Outcome Over Time

**Outcome #6 Successfully Achieved; Kentucky and Nationwide. 2005/2006 through 2009/2010**



Source: The 2009-2010 National Survey of Children with Special Health Care Needs

## What our community is saying .

*"Help more kids find work, education, not just rely on government assistance as a career goal"*

-Rowan Co., Morehead Region

*"Programs for adults that have special needs after graduation"*

-Carter Co., Ashland Region

*"Education for transition from child, teenager to adult"*

-Laurel Co., Barbourville Region

*"GED program"*

-Jefferson Co., Louisville Region

*"IQ testing, jobs for individuals with disabilities"*

-Barren Co., Bowling Green Region

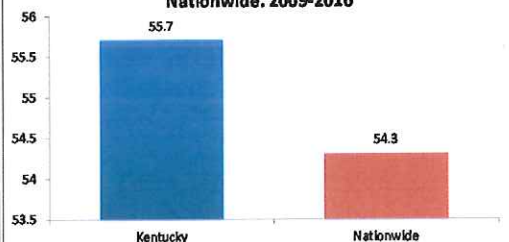
*"Transition services for young adult with autism"*

-Jefferson Co., Louisville Region

## *"Peer groups and counseling for teens"*

-Bourbon Co., Lexington Region

**CSHCN who did not receive all needed guidance transitioning to adult health care; Kentucky and Nationwide. 2009-2010**

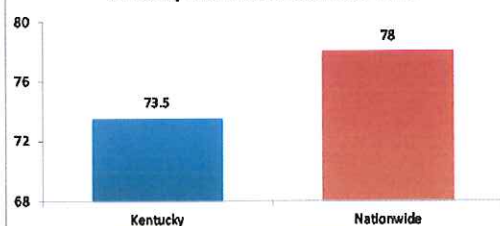


Source: The 2009-2010 National Survey of Children with Special Health Care Needs

## *"Finding a way to get kids to talk to you about problems they are having"*

-Morgan Co., Morehead Region

**CSHCN encouraged to take responsibility for self-management of health care needs; Kentucky and Nationwide. 2009-2010**



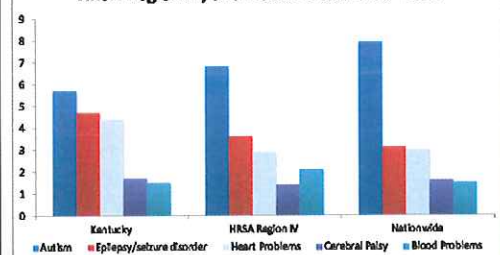
Source: The 2009-2010 National Survey of Children with Special Health Care Needs

## Prevalence of 18 conditions

- The 2011/2012 NS-CSHCN looks at 18 chronic health conditions
  - Not a comprehensive list, but meant to cover a broad range of conditions
- Condition Questions
  - For each condition, please tell me if a doctor or other health care provider ever told you that (child's name) had the condition, even if (he/she) does not have the condition now
  - For each condition child has had, does child currently have this condition?
  - For each condition, would you describe this condition as mild, moderate or severe?

## Conditions

**Prevalence of certain conditions; Kentucky, HRSA Region IV, and Nationwide. 2009-2010**



Source: The 2009-2010 National Survey of Children with Special Health Care Needs



### What community members are saying...

*"I wish they had more pediatric neurologists where I live we go all the way to Louisville . . . Also more [pediatricians]"*

-Ohio Co., Owensboro Region

*"More dental offices that take medical card more cardiology or neurology or more programs for children with special needs in Ohio Co and a better hospital"*

-Ohio Co., Owensboro Region

*"I have to take a grandson to Nashville for his spina bifida, need Drs. for him in our town or closer"*

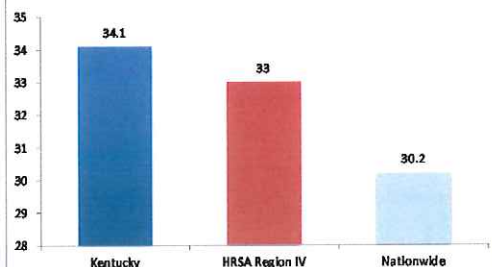
-Graves Co., Paducah Region

*"Anything related to depression, anxiety & ADHD would be beneficial to our family"*

-Carter Co., Ashland Region

### ADD/ADHD

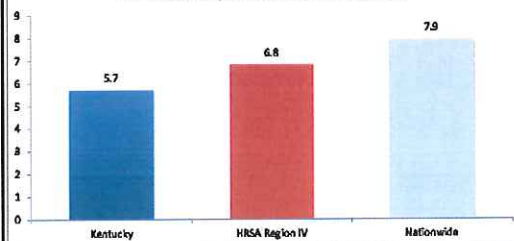
#### Kentucky, Region IV, and Nationwide CSHCN with ADD or ADHD, 2009-2010



Source: The 2009-2010 National Survey of Children with Special Health Care Needs

### Autism

#### Kentucky, Region IV, and Nationwide CSHCN with Autism, Asperger's Disorder, pervasive developmental disorder, or other autism spectrum disorder, 2009-2010



Source: The 2009-2010 National Survey of Children with Special Health Care Needs

### Our community members are saying...

*"Support for ADHD children & auditory processing children"*

-Davless Co., Owensboro Region

*"OT for autism feeding issues in Hardin County, right now must go to Louisville"*

-Hardin Co., Elizabethtown Region

*"Services for autism cause no one wants to deal with it"*

-Powell Co., Lexington Region

*"Behavioral Health, FASD, Autism treatment"*

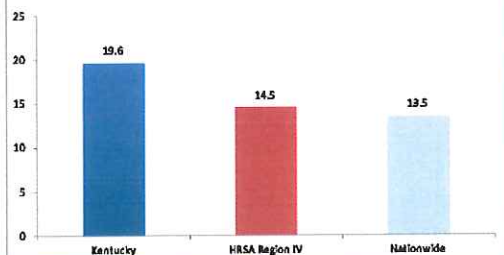
-McCracken Co., Paducah Region

*"Autism counseling awareness"*

-Muhlenberg Co., Owensboro Region

### Behavioral or Conduct Problems

#### Kentucky, Region IV, and Nationwide CSHCN with behavioral or conduct problems, such as oppositional defiant disorder or conduct disorder



Source: The 2009-2010 National Survey of Children with Special Health Care Needs

### Our community members are saying...

*"Social group therapy for children with high functioning autism"*

-Hardin Co., Elizabethtown Region

*"Support for grandparents raising grandchildren. Support groups and services for grandparents raising grandchildren with Autism"*

-Hardin Co., Elizabethtown Region

*"I would like to see a support group for parents who have unruly kids that are hard to control due to autism, Asperger's syndrome, etc."*

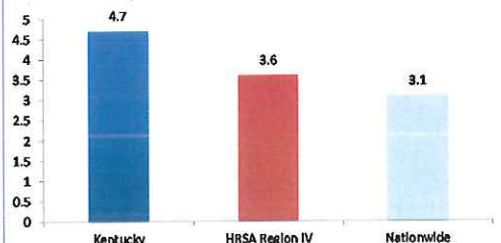
-Fleming Co., Morehead Region

*"A 'play center' for children with autism and other developmental delays to practice social skills and learn by the opportunity to take classes that other children are able to take in the community (e.g. gymnastics, dance, art, yoga)"*

-Fayette Co., Lexington Region

## Epilepsy

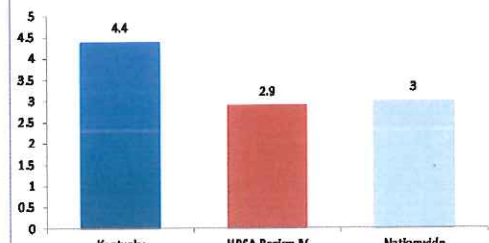
**Kentucky, Region IV, and Nationwide CSHCN with Epilepsy or seizure disorder. 2009-2010**



Source: The 2009-2010 National Survey of Children with Special Health Care Needs

## Heart Problems

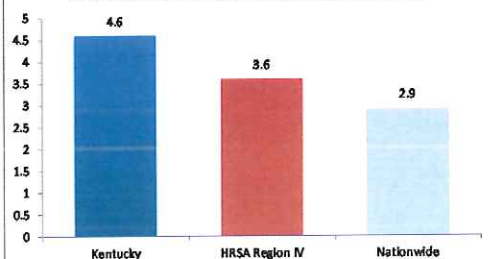
**Kentucky, Region IV, and Nationwide CSHCN with heart problems, including congenital heart disease. 2009-2010**



Source: The 2009-2010 National Survey of Children with Special Health Care Needs

## Arthritis

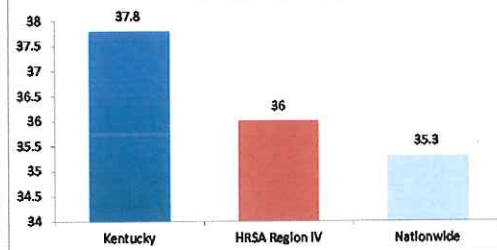
**Kentucky, Region IV, and Nationwide CSHCN with Arthritis and other joint problems. 2009-2010**



Source: The National Survey of Children with Special Health Care Needs

## Asthma

**Kentucky, Region IV, and Nationwide CSHCN with Asthma. 2009-2010**

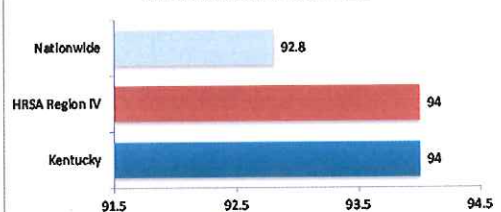


Source: The 2009-2010 National Survey of Children with Special Health Care Needs

*"More support for children with special needs and their families and more resources in general to help meet their physical, educational and emotional needs"*

-Butler Co., Bowling Green Region

**CSHCN whose families have no unmet need for family support services; Kentucky, Region IV, and Nationwide. 2009-2010**



Source: The 2009-2010 National Survey of Children with Special Health Care Needs

## What community members are saying...

*"Behavioral therapies, pediatric psychiatry"*

-Russell Co., Somerset Region

*"Better access to therapies. Opening of Sensory clinics specifically for those with special needs"*

-Warren Co., Bowling Green Region

*"In home peer support services and behavioral health services"*

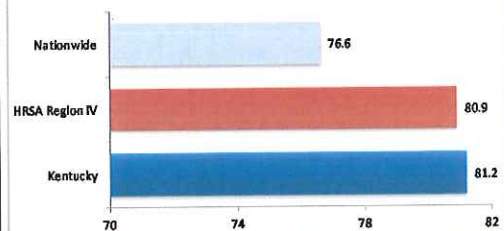
-Franklin Co., Lexington Region

*"More interactive programs for children with behavioral issues due to parenting skills, or lack of parents"*

-Henderson Co., Owensboro Region

*"Better doctors in our area"*

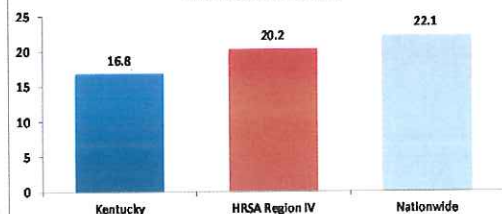
-McCreary Co, Somerset Region

**CSHCN who had no problem getting needed referral;  
Kentucky, Region IV, and Nationwide. 2009-2010**

Source: The 2009-2010 National Survey of Children with Special Health Care Needs

*"Assistance with therapy needed items"*

-Davess Co, Owensboro Region

**CSHCN whose families pay \$1,000 or more out of pocket in  
health-associated costs; Kentucky, Region IV, and  
Nationwide. 2009-2010**

Source: The 2009-2010 National Survey of Children with Special Health Care Needs

**What community members are saying . .***"Assistance with medical bills"*

-Fleming Co., Morehead Region

*"Help finding a place to live"*

-Bourbon Co., Lexington Region

*"Housing"*

-Jefferson Co., Louisville Region

*"Section 8 Housing"*

-No county noted

*"Rent help electric help"*

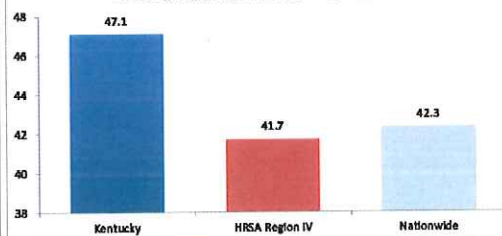
-Jefferson Co., Louisville Region

*"Michele P Waiver—assessed but not approved due to funding issues"*

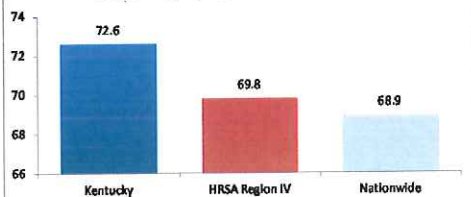
-Christian Co., Bowling Green Region

*"She doesn't get everything she needs through school and her Dr.  
is in Cincinnati"*

-Fleming Co, Morehead Region

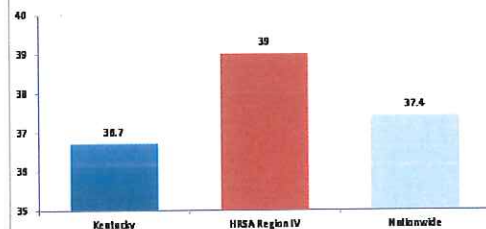
**CSHCN who meet all components of care coordination;  
Kentucky, Region IV, and Nationwide. 2009-2010**

Source: The 2009-2010 National Survey of Children with Special Health Care Needs

**CSHCN who have a little or a lot of difficulty  
with one or more bodily functions; Kentucky,  
Region IV, and Nationwide. 2009-2010**

Source: The 2009-2010 National Survey of Children with Special Health Care Needs

Bodily functions, such as: breathing or respiration, swallowing or digestion, blood circulation, chronic physical pain including headaches, seeing even when wearing glasses or contacts, hearing even when using a hearing aid

**CSHCN screened for being at risk for developmental,  
behavioral & social delays using the SDBS tool during a  
health care visit**

Source: The 2009-2010 National Survey of Children with Special Health Care Needs



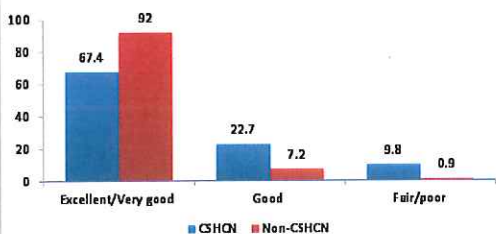
## Looking at disparities...

## The National Survey of Children's Health

- Conducted in the same manner as the NS-CSHCN, by the same agencies
- Conducted in the years 2003, 2007, and 2011/2012
- Focuses on multiple aspects of children's lives
  - Health status
    - Physical, mental, developmental
  - Access to care
  - Information on child's:
    - Family, neighborhood, social environment
- ❖ Can compare CSHCN with non-CSHCN
  - NSCH shows the subpopulations at particular risk for each indicator, so significant differences are clear
  - Uses the CSHCN Screener tool to identify children with special health care needs

## Health Status of Kentucky CSHCN

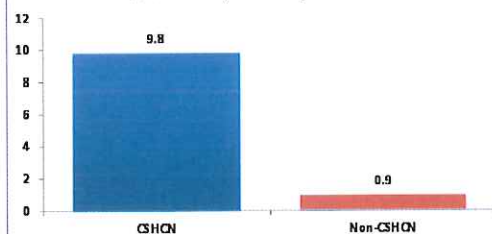
Health Status of CSHCN vs. non-CSHCN, Kentucky, 2011-2012



Source: The 2011-2012 National Survey of Children's Health

## Fair/Poor Overall Health Status

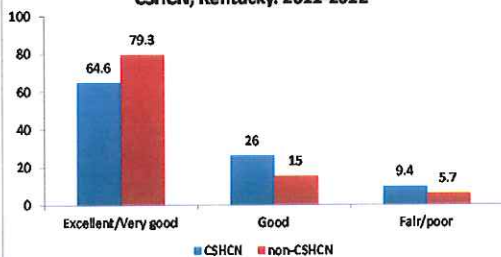
CSHCN and Non-CSHCN with fair or poor overall health status; Kentucky, 2011-2012



Source: The 2011-2012 National Survey of Children's Health

## Condition of CSHCN's Teeth

Overall Condition of Teeth in CSHCN and non-CSHCN; Kentucky, 2011-2012



Source: The 2011-2012 National Survey of Children's Health

## What community members are saying...

*"Needs a dentist in E KY that takes CSHCN"*  
-Johnson Co., Prestonburg Region

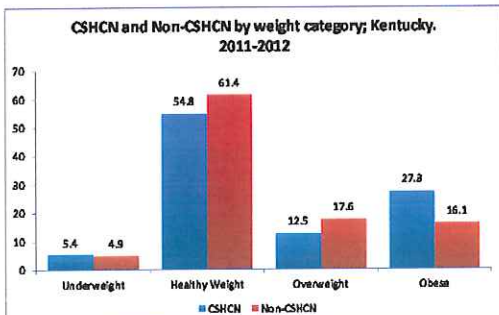
*"Orthodontics and autism specialist"*  
-Warren Co., Bowling Green Region

*"Si el dentist"*  
-Montgomery Co., Morehead Region

*"Better dental coverage"*  
-Graves Co., Paducah Region

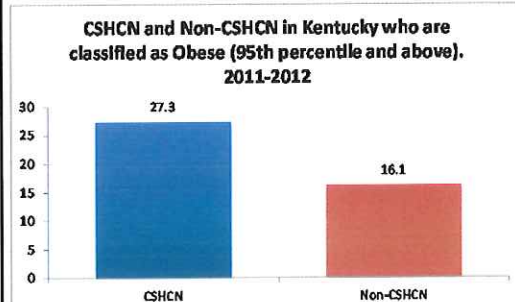
*"More dental offices that take medical card"*  
-Ohio Co., Owensboro Region

### Weight breakdown of CSHCN



Source: The 2011-2012 National Survey of Children's Health

### Disparities in the Obese Weight Category



Source: The 2011-2012 National Survey of Children's Health

### What community members are saying...

*"Are there summer camp programs for like my child with cost efficiency in mind"*

-Jefferson Co., Louisville Region

*"More opportunities for my 9-year-old daughter with developmental disabilities to participate in her community and be with peers. We would love to see a special needs soccer group, cheerleading group or social group. She does not have autism or Down Syndrome, and most of the programs in my community are for children with those specific diagnoses. Very frustrating. Like her disability is not that bad and she doesn't need special services, but she only has an IQ in the low 50s"*

-Jefferson Co., Louisville Region

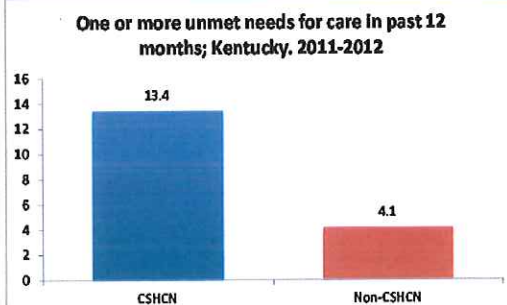
*"Special needs playground equipment at public parks"*

-Warren Co., Bowling Green

*"More activities for kids"*

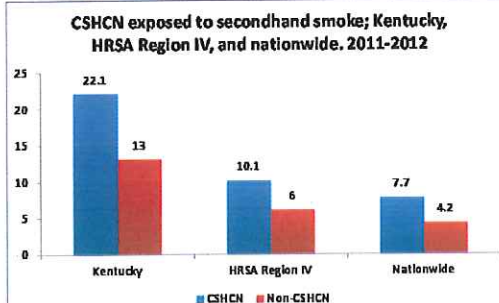
-Harding Co., Elizabethtown

### CSHCN with Unmet Needs for Care



Source: The 2011-2012 National Survey of Children's Health

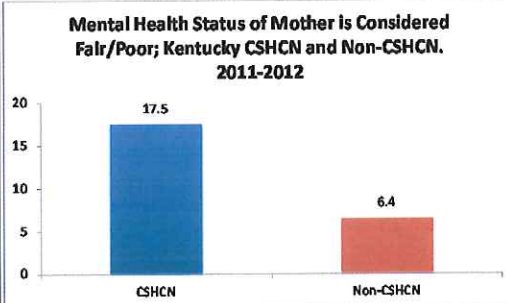
### Exposure to Secondhand Smoke; Smoking in Child's Home



Source: The 2011-2012 National Survey of Children's Health

*"Hopeless and not know what to do with SN child"*

-McCreary Co., Somerset Region



Source: The 2011-2012 National Survey of Children's Health

### What community members are saying...

*"Behavioral health services-Our community is really lacking in this area!"*  
--Calloway Co., Paducah Region

*"Family Counseling Help keeping families together"*  
--McLean Co., Owensboro Region

*"Support groups that is advertised to help you as a parent cope with  
your child's issues as well and cope as a family and make it work"*  
--Rowan Co., Morehead Region

*"Child care"*  
--Warren Co., Bowling Green Region

*"Increased respite hours"*  
--Kenton Co., Lexington Region

*"In home help reliable"*  
--Webster Co., Elizabethtown Region





# Kentucky Supporting Documents: CYSHCN

---

Commission for Children with Special Health Care Needs

**On the Following Page:**

**Data Brief: CYSHCN Disparities**



Commission for Children with  
Special Health Care Needs

# Disparities faced by Kentucky Children with Special Health Care Needs: A Comparison to the Kentucky Non-CSHCN Population

## Medical Home Components

1. Has at least one person they think of as a personal doctor or nurse
2. Has usual source of care for when they are sick
3. Family-centered care
4. Children have no problems getting needed referrals
5. Care coordination is effective and comprehensive
6. Specialists can be accessed, if needed

Receives ongoing , comprehensive, coordinated care within a medical	Kentucky Non CSHCN	Kentucky CSHCN
Cares does NOT meet criteria for having a medical home	39.6%	55.3%
Care meets crite- ria for having a medical home	60.4%	44.7%

## Needs for Care

% of Kentucky children with one or more un-  
met needs for care during the past 12 months

- ◇ CSHCN: 13.4%
- ◇ Non-CSHCN: 4.1%

## Medical Home

The medical home concept is a family/patient focused model of health care centered around meeting all patient needs through the coordinated, comprehensive effort of a team of medical professionals led by a physician. The team then coordinates care for the individual patient, aiming to increase the efficiency of receiving needed treatment by integrating services into a single, working unit.

% of Kentucky children who did not receive one or more care coordination components within the past 12 months

- ◇ CSHCN: 36.2%
- ◇ Non-CSHCN: 8.1%

% of Kentucky children who received all care components, effectively, over the past 12 months

- ◇ CSHCN: 42.7%

In Kentucky, CSHCN, as compared to non-CSHCN, are more likely to *not* meet all the combined criteria for receiving care within a medical home.

## Health Insurance Coverage

% of Kentucky children uninsured at time of survey

- ◇ CSHCN: 3.7%\*
- ◇ Non-CSHCN: 4.4%

### Type of Health Insurance covering Kentucky children

% of Kentucky children on Public Insurance

- ◇ CSHCN: 56.1%
  - ◇ Non-CSHCN: 36.4%
- % of Kentucky children on Private Insurance
- ◇ CSHCN: 40.1%
  - ◇ Non-CSHCN: 59.2%

% of Kentucky children with adequate insurance coverage that meets  
needed services

- ◇ CSHCN: 75.1%
- ◇ Non-CSHCN: 78.6%

## Discussion...

Such data reveals that, compared to their non-CSHCN counterparts, Kentucky CSHCN are more likely to go without receiving all needed care over the course of 12 months. Kentucky CSHCN are also more likely to be on public insurance versus private insurance, wherein the opposite is true for Kentucky non-CSHCN. Differences looking at adequate insurance coverage and the number of uninsured children in the state did not result in significant results.

### Oral Health/Dental Care

% of Kentucky Children with Condition of Teeth Described as Excellent/Very Good Condition:

- ◇ CSHCN: 64.6%
- ◇ Non-CSHCN: 79.3%

Overall Health Status	KY Non CSHCN	KY CSHCN
Excellent/Very	92.0%	67.4%
Good	7.2%	22.7%
Fair/Poor	0.9%*	9.8%

\*=based on sample sizes too small to meet standards for reliability.

### Healthy Weight

% of Kentucky Children described as Underweight, as determined by BMI for age

- ◇ CSHCN: 5.4%
- ◇ Non-CSHCN: 4.9%

% of Kentucky Children with Healthy Weight

- ◇ CSHCN: 54.8%
- ◇ Non-CSHCN: 61.4%

% of Kentucky Children who are Overweight

- ◇ CSHCN: 12.5%
- ◇ Non-CSHCN: 17.6%

% of Kentucky Children who are Obese

- ◇ CSHCN: 27.3%
- ◇ Non-CSHCN: 16.1%

### Smoking in Household and Exposure to Secondhand Smoke

% of Kentucky children who have someone who smokes in their home, thus exposing them to the risks of secondhand smoke

- ◇ CSHCN: 22.1%
- ◇ Non-CSHCN: 13.0%

% children who have a household with *no* tobacco use

- ◇ CSHCN: 53.4%
- ◇ Non-CSHCN: 63.4%

#### What the data tells us . .

In general, Kentucky CSHCN face a multitude of disparities when compared to non-CSHCN within the state. Data provided by the NS-CH illuminates issues addressing health and factors that may influence the well-being of children living in Kentucky, particularly in regards to the subject of medical home, oral health, home environment in regards to exposure to secondhand smoke, weight status, neighborhood support, and

school engagement.

In Kentucky, CSHCN, as compared to non-CSHCN, are less likely to have teeth described as excellent/very good condition, and CSHCN ages 6-17 are less likely to be consistently engaged in their schoolwork.

Furthermore, KY CSHCN are more likely to be described as obese based on BMI-for-age and less likely to have a healthy weight. Com-

### School Engagement

% of Kentucky Children ages 6-17 Consistently Engaged in School

- ◇ CSHCN: 64.5%
- ◇ Non-CSHCN: 83.3%

### Supportive Neighborhood Environment

% of Children who Live in Supportive Neighborhoods

- ◇ CSHCN: 78.9%
- ◇ Non-CSHCN: 82.6%

**Supportive Neighborhood Environment** is a series of survey components addressing criteria such as accountability of neighbors, whether or not neighbors watch out of each others' children, and whether or not parents could depend upon a neighbor if their child was alone and scared or hurt.

pared to their non-CSHCN

counterparts, they are much less likely to have excellent/very good overall health status, but more likely to have good health status.

Such information illuminates the need for specialized services in order to appropriately address the healthcare needs and emotional well-being of the CSHCN population.